

Health and Hardship:

Stories from 9/11's Unsung Heroes



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Introduction

This year marks the 14th anniversary of the attacks of 9/11 and the collapse of the World Trade Center (WTC). As we pause to remember and honor the nearly 3,000 lives lost that day, we also remember and honor the first responders who answered the call and risked their lives to support New Yorkers in a time of great need. These responders are now suffering from chronic and fatal illnesses—as are the area workers, residents, and students (referred to as survivors)—after exposure to the WTC-derived contaminants. It is estimated that over 400,000 people in total were exposed. Of the people exposed, 90,000 were responders involved in the rescue, recovery, and cleanup effort. Responders and survivors were both exposed to numerous WTC-derived contaminants that included roughly 70 carcinogens and other hazardous substances¹. In the years following 9/11, these responders and survivors have experienced significant illnesses related to their exposure. The evolution of their symptoms nearly fifteen years later has proven the necessity of long-term medical care for our country's 9/11 heroes and Lower Manhattan residents and workers.

In 2011, the James L. Zadroga 9/11 Health & Compensation Act was passed after an enormous collective effort from the 9/11 responder and survivor community and their champions in Congress. The Zadroga Act established the WTC Health Program, which provides medical monitoring and treatment for 9/11 responders and area workers, residents, and students. Several clinics in the New York Metro Area are part of the Program along with a national program that can treat responders and survivors in locations throughout the United States (see page 44 for list of NY Metro Area clinics). WTC-related health conditions may be monitored and treated under this legislation.

Health and Hardship: Stories from 9/11's Unsung Heroes is a compilation of first-person accounts from 9/11 responders who recall their experiences and later managing their WTC-related health conditions. The responders interviewed for this report are patients at the Icahn School of Medicine at Mount Sinai, one of the Clinical Centers of Excellence in the WTC Health Program administered by the National Institute of Occupational Safety and Health. Their stories bring to light the health hazards present during the disaster, the impor-

1. Newman, DM. 2014. Protecting Worker and Public Health During Responses to Catastrophic Disasters—Learning From the World Trade Center Experience. *American Journal of Industrial Medicine* 57: 1295-98.

tance of providing protections for responders in future disasters, and the need to secure for today's 9/11 responders the healthcare they need in the future.

We had the distinct honor of interviewing these responders who shared incredible stories highlighting the significant ways in which 9/11 is still a major public health concern 10+ years later. The responders' selflessness is striking. Amidst the confusion, panic, and devastation, they ran towards danger, without regard to how their own health would be impacted. Almost all responders said they would do the work again even now knowing full well the consequences of working in a hazardous site. They all considered themselves the lucky ones in the disaster for having survived, even while experiencing symptoms of 9/11-related conditions.

Our hope is that their stories will be enshrined in our nation's history and will encourage us to better protect first responders from debilitating, exposure-related illnesses. We must learn from their experiences and restructure preparation for disasters and emergencies so we can better protect workers, anyone who could be exposed, and the environment. So often, the first-hand experiences of workers is lost or overlooked when occupational safety and health hazards, illnesses, and injuries are analyzed. Each story is accompanied by commentary from medical providers at Mount Sinai on one specific 9/11-related condition the responder is enduring. Many responders are suffering from numerous 9/11-related conditions as well as conditions that are medically associated with their 9/11-related conditions.

NYCOSH wishes to acknowledge and thank the 9/11 responders who shared their personal stories, thereby making this publication possible. These brave individuals exemplify courage and strength both by their actions during the 9/11 disaster, and in sharing their heartfelt stories. We believe their honesty will continue to inspire the 9/11 responder and survivor community at large.

***This report captures the experiences of a select group of responders and thus these stories do not reflect the totality of the response efforts or the experiences of survivors who were also heavily impacted by WTC exposure. Please note these interviews were edited to ensure clarity and conciseness. Selected physicians and medical providers are not necessarily the treating provider for the indicated patient. Medical providers commented on certified conditions in a general manner.

Daisy Bonilla

AGE: 47

OCCUPATION: School Safety Agent
(New York Police Department)

CURRENT STATUS: In the process
of retiring

INVOLVEMENT IN 9/11

RESPONSE EFFORTS: Patrolling and
securing the disaster area



I worked for the NYPD as a School Safety Agent and the day that it happened I was working at School for the Physical City High School on 28th Street between Park and Madison. It was a junior high and high school. That day a lot of the kids were doing photography and they went out to take pictures. Two ran back and said one of the Twin Tower buildings went down and we told them to stop lying, but then we went to a room and turned on the news. We kept students in their classrooms and notified teachers of what was going on, and then we started the evacuation. A lot of kids went home. My work partner left the building because she had a lot of family that worked at WTC. She lost a lot of cousins.

On the second day, everyone at NYPD school safety started doing their long shifts. That day we went down to Ground Zero and I was patrolling. I was with twelve other guys around William Street and Fulton Street. All the debris fell on our arms down there and it was so itchy we scratched so bad we ripped the skin. I could feel the glass on my skin; all the white stuff was just coming down. Everything that was in the buildings was on us. We didn't have any masks.

We went to the Red Cross that was located at Pace University and there was a doctor who took care of us. She cleaned us up, gave us tetanus shots and other medications, and she told our Lieutenant that we had to rest for eight hours before we could go outside again, so we did. Then they put us back out. We were patrolling the area because there were people trying to get back into their buildings to retrieve things, but no one could come back at that point. We were helping out the Police Officers with traffic and we were looking around to see if anyone needed help.

When I got home, I told my mother to bring out a black garbage bag and I took everything off—boots and everything—and then threw it away. School safety told us when we went home to take off our clothes and put them in a black bag and to call them so they could dispose of it. They told us to not bring anything in the house; they told us nobody should touch us. I had a lot of itching. When I was walking in the area, I tried to cover my eyes. We were breathing it in.

We did a lot of overtime. This went on for months. We would walk around the area to Red Cross locations and different schools that were open as shelters wherever anybody needed help. I saw a lot of things and I never discussed it. When it happened, I was still in shock. We don't want to believe that it's actually happening to us. I didn't want to believe it. I didn't think about all the stuff that we were breathing in. What I was thinking about was helping the people down there, helping the people that were in trouble. I didn't think about the fact that we looked like ghosts with all the debris.

I used to put my conditions on the back burner. When people would talk about the incident, I would walk away; I didn't want to deal with it. I would go to different doctors to get my skin checked out but because they didn't see any rashes or blisters or anything, they told me I was probably allergic to something. I also filed a C-2 package and gave it to my supervisor for workers compensation when the debris fell on me so I already had a workers compensation case from this, but I never followed up. Later on, I developed asthma again. I used to have asthma as a kid but it went away. I have sleep apnea and I have chronic rhinitis. I have gastroesophageal reflux disease GERD—acid reflux—real bad. The GERD has affected my gastrointestinal system so much that I have limited and weak peristaltic function now. I have chronic sinusitis, PTSD, and obstructive airway disease. I have Systemic Lupus Erythematosus, an autoimmune disease that also results in antiphospholipid syndrome, which is excessive blood clotting. I have a lot of inflammation and a lot of pain in my joints. I don't sleep well at night. I take off the CPAP mask² because I feel like I am suffocating. I do use it, but in the middle of the night I take it off. I did the sleep test two weeks ago. When I went to sleep, I stopped breathing twenty three times and when I went into a deep sleep, I stopped breathing seventy seven times.

I have a lot of muscular pain and that's what prevents me from working. I can walk a block and half but I have to stop because I get pins and needles, a burning sensation, and it feels like my skin is ripping off. I take a lot of pain medication but it doesn't help. I can't do a lot of the things that I used to do. I can't do sports; I can't go out dancing, even if my friends want me to. It's not fun to just sit there. My voice is deeper; I have a lot of post-nasal drip and at least once a month I lose my voice for about a week or so. I also had surgery on my vocal cords because I had polyps.

I am in the process of retiring because of sickness. I did my job for twenty years and eight months. I just needed four and half more years to retire, but due to my conditions I couldn't do that. So I got the short end of the stick. It helps that the Program covers a few of my conditions.

2. Continuous positive airway pressure (CPAP) machine helps a person who has obstructive sleep apnea (OSA) breathe more easily during sleep. A CPAP machine increases air pressure in the throat to prevent the airway from collapsing while breathing in.

You know school safety is not recognized for the role they played in the response. You don't hear anything about us. We worked doing the same thing, and there's no acknowledgement of that at all. They pushed us aside and that hurts me.

I used to talk to the kids at the schools I was working at. A lot of them lost parents that day. There was this one kid that always used to say what you need to do is close your eyes and relax and picture someplace else—go to a happier place. This kid lost his parents and he was telling me that. The kid was strong. What he used to tell me, I used to tell to the other kids. I would tell them to picture someplace else, someplace happy.

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MUSCULOSKELETAL INJURY CONDITION –

Comments of Michael Crane, MD, MPH, Occupational and Preventative Medicine, Medical Director World Trade Center Health Program Clinical Center at Mount Sinai

WHEN RESPONDERS COME to the clinic, one of the hardest things I often have to do is tell them that I can't do anything for them because of the current regulations on certified musculoskeletal injuries. It's truly unfortunate.

We saw a number of patients who had repetitive motion injuries, like carpal tunnel syndrome. We treated slip and fall injuries, back injuries, lifting injuries, knee and ankle injuries, abrasions, burns, sprains and fractures. Responders climbed through the remnants of the tower, balanced on beams to search for bodies and perform cleanup, and all the while had burning debris falling on them, so the injuries were severe.

Musculoskeletal injuries have a very long tail and gait deterioration, seen over a long period of time. Many of the patients originally seen with serious hip and knee injuries are now demonstrating gait deterioration and require surgery to replace the affected joint. Maintaining mobility is really important. There's a built-in benefit in our ability to be healthy and live in a community if we're mobile. When people become limited in their mobility, it's a sign that things may go badly. We need to keep patients moving. Mobility is an important facet of everybody's health.

We don't yet know all of the impacts the trauma of 9/11 may continue to have on the musculoskeletal system. For example, many of the patients we treat have asthma and use steroids, which wreak havoc on bones. Patients can have so much bone disease that they fracture bones when they cough, and they cough a lot because of the asthma, so there's a strong negative feedback component in play. We don't yet know the potential harmful impact that all of the medications used by these patients for other 9/11-related conditions may have on the musculoskeletal system. Studies need to be done now on this topic. As our patients age, their musculoskeletal systems naturally get weaker. Musculoskeletal decline is a critical issue. Maintaining patient mobility and a patient's ability to be in their community is paramount because it's one of the key signs that they're holding on to their good health.

We don't yet know all of the impacts the trauma of 9/11 may continue to have on the musculoskeletal system.

John R. Soltes

AGE: 62

OCCUPATION: Police Officer
(Port Authority Police Department)

CURRENT STATUS: Retired

INVOLVEMENT IN 9/11 RESPONSE

EFFORTS: PAPD Rescue/Recovery



On 9/11, I was retired from the Port Authority Police Department (PAPD), but when the incident

happened I went into my precinct at the George Washington Bridge. I tried to get down there on 9/11, but everything was closed off. So on the evening of 9/12—my first response out to the pit³—I went out and stayed for eight and a half months. I didn't leave until May 30th, 2002. There were twelve of us retirees that came back to work for the rescue/recovery unit. They welcomed us with arms open; they needed all the help they could get. We were dubbed team Romeo, the 'R' being the phonetic alphabet letter 'R' for "retired."

On 9/12, we reported to the Port Authority Headquarters down there and worked the midnight shift. We got in at about 3:00 p.m. and worked until about 7:00 a.m. For the first month, we worked seven days a week. There was no break. You'd go home to catch up on some sleep or you'd sleep down there since we had tents set up at the time with cots. Eventually it went down to twelve hour shifts, and then eight hour shifts, but pretty much five, six, seven days a week.

For about the first two weeks, there was very little protective gear. Paper masks were handed out but no respirators for about the first two weeks. A lot of the boots that were issued melted. I think I went through four sets of boots. The metal was still so hot that we were walking on.

We didn't have to go through any training to work on the pit. They were at first starving for volunteers; they needed everybody down there. When they issued respirators, probably about two weeks in, there was still no training about how to use them. It wasn't until about two months in that they issued the respirators with replacement filters. At first they never told us that the filters were only good for eight hours. So we were walking around with filters on for weeks, that didn't fit our faces. Eventually, they had a trailer set up. They would bring us into the trailer and fit us with the masks and that's when we found out that we weren't supposed to be using these filters for weeks at a time.

3. A term often used by 9/11 responders to refer to the WTC site.

At the time, there was only one thing on our mind and that was getting the job done. It was finding as many people as we could and nobody really thought about their personal health. When I think back, yeah, we were coughing. Like I said, the best way to find a body was through smell and to do that you had to take your respirator off and the goggles they issued—you couldn't see anything through them—so I very rarely ever wore my goggles because you couldn't see anything. It was almost more dangerous to wear them so I took them off. There were a lot of things going on. Looking back, a lot of us were suffering from PTSD and breathing problems. Everyone developed what they call the WTC cough, but we didn't think anything about it. All we wanted to do was the job at hand. We didn't think anything about personal health at the time. A lot of the things we saw or did that were horrible, we didn't think about until we were done. We would leave that place and would cough and spit up black dust, all kinds of crap. It just felt like we had to go back and do it all over again. We put everything on the back burner, so to speak.

It was rough particularly for the retired guys. We went back to retirement and basically had nothing to do, nothing to keep ourselves busy. For the other guys who went back to work, they had that to lean on. For us, we didn't have much to lean on and so we formed this organization, "9-11 Cops." We get together every Tuesday. We just celebrated our 605th consecutive get-together. It is basically a bunch of Port Authority cops and New York City cops who worked at Ground Zero together.

I have been coming to Mount Sinai since November of 2002. I am very, very grateful to Mount Sinai. They've found a lot of things wrong with me. I am certified for sleep apnea, which I had never had before. At first it affected my home life a lot but then as treatment went on, it alleviated a lot of the problems. There was a lot of worry involved; quite frankly I was scared. I didn't know anything about these ailments. I couldn't eat anything with any kind of spice. They actually found that I have the start of Barrett's Esophagus, which is a precursor to cancer in the esophagus. It's scary because every time that I come for my medical monitoring, once every twelve months, I get a little worried because you never know. You hear the horror stories of guys getting all sorts of cancers. Quite a few guys have died because of 9/11. Everybody that I know who has worked down there has conditions.

I have been in therapy since March of 2002. It has helped out a lot. I often tell people to this day that I am still tired from it. It was exhausting, but you had to keep going. I swear I lost something down there and I just never got it back. I talked to a lot of people like that who feel the same way.

If it happened tomorrow, everyone that I hang out with would do the same thing. Obviously I would like to see more safety precautions from the onset. Now we know that you can't go to a site like that without respirators.

It was exhausting, but you had to keep going. I swear I lost something down there and I just never got it back. I talked to a lot of people like that who feel the same way.

It's something that none of us will ever forget. First of all, I think it's very important that we don't forget. Like the old saying—you learn from history, you know what to do better in the future.

I owe a lot to my family. They made sure I took care of myself the best way that I could. My wife and my kids were good friends with the guys who were lost too. We were family. It wasn't only me, everyone was involved in this. It touched everybody.

CHRONIC GASTROESOPHAGEAL REFLUX DISEASE (GERD) – Comments of Benjamin L. Cohen, MD, MAS, Assistant Professor of Medicine, Gastroenterology

I KNEW THAT many of the responders had been experiencing a lot of GI symptoms since their exposure down at WTC and it seemed like a really good chance to help out people who had been deeply affected.

Chronic gastroesophageal reflux disease (GERD) is a common condition seen in 9/11 responders. GERD is a digestive disorder in which stomach acid travels back up into the esophagus. We're not sure which particles or fumes in the dust cloud contributed to this condition, but it's clearly related.

Chronic reflux can cause precancerous changes in the lining of the lower esophagus, known as Barrett's Esophagus. Although the progression of Barrett's Esophagus into cancer is very low, many patients are worried about it. Having chronic reflux for years and years theoretically puts these patients at a higher risk of acquiring Barrett's Esophagus, but the pathophysiology is still not completely well understood.

In some patients we have seen GERD evolve into a form of intractable reflux. It may not respond to any medications and quality of life can be very poor because of constant symptoms. In addition, a lot of patients are at an age where you wouldn't expect them to be having such severe reflux symptoms. Reflux is a common problem, but the difference is that some of the 9/11 responders appear to be less responsive to the medical therapies.

Patients who continue to have symptoms despite the medical therapies, have changes in their symptoms, or have Barrett's Esophagus, require more frequent endoscopies. Patients may also require more specialized testing due to the fact that there are more patients in this cohort with severe medically refractory disease.

GERD may also affect these patients' pulmonary and sinus health because acid can travel into the larynx, throat, or lungs. Chronic GERD may contribute to the sensation that they can't swallow or breathe and act as a chronic irritant. While I think some of the other disease processes patients may have in other organ systems as a result of their WTC exposure may be perceived as worse than those of the GI system, a lot of the GI symptoms are actually contributing to the worsening of other conditions.

A lot of the common medications used in reflux treatment, while they're safe, have potential for some long term side effects. For example, proton pump inhibitors may put patients at a small increased risk for fractures with long term use, and can also increase the risk of certain gastrointestinal-related infections or pneumonia. So while they are generally safe, taking them for 10-20 years poses problems for patients. This may be an issue we are going to start seeing in this population.

In the next 10 years, we may see a continued progression of gastrointestinal disease that leads to elevated rates of colon polyps or colon cancers as compared to the general population. We don't know that WTC exposure would cause them to have colon polyps or cancer, but we have seen increased risks of developing various other types of cancers. Close monitoring of the results from the colon cancer screening program will be important. A lot of this is undiscovered territory, very much like the pathophysiology of Barrett's Esophagus and GERD itself, but it's something that needs to be studied and reported on.

Joe McCauley

AGE: 60

OCCUPATION: Computer

Support Consultant

CURRENT STATUS: Full-time

INVOLVEMENT IN 9/11 RESPONSE

EFFORTS: Volunteer at NYC Office of Emergency Management (OEM)



I was about 5 blocks away when the incident happened. I was working for a consulting agency at the time called Computer Horizons. Computer Horizons consultants were spread all over different agencies in the city. At the time I was working at the NYC Department of Citywide Administrative Services (DCAS), on 1 Centre Street, the municipal building. That's where I was when the planes hit. I left the city pretty quickly. But about a day or two later, I got a phone call from friends who were looking for somebody to take over their shift at the Office of Emergency Management (OEM). They had a center set up over on Chambers and West Street. They had a couple of laptops and a printer and they just needed somebody there. So I volunteered to go down.

I had never worked with OEM before. They just needed somebody to keep the network up. There were a lot of miscellaneous things that happened. A firefighter came in with a hand drawn map and he wanted to make the map bigger and make copies of it so he could hand it out. The whole area was a disaster and there were no accurate maps at that moment of the area. Our location, Chambers and West Street, was about four blocks from Ground Zero. I could see all the arms of the cranes lifting things up and trucks going by with huge pieces of twisted steel and some crushed and twisted fire engines. I was there the first week.

There was thick dust everywhere. They had very quickly put up some filtering equipment outside the windows where we were located. We were in an elementary school auditorium. It was the most convenient spot to authenticate all the thousands of people that came to help. There were so many people from all over trying to help and trying to get down there but they all needed an ID card of some kind. The ground was pretty much still covered in this dust, and what they had done was swept up all the dust into the playground at the base of the trees like little pyramids. Since we had filters on the outside of the building we weren't wearing any masks there. We were giving them out though; we had a lot of supplies, like boots, masks, and medical supplies. A lot of people came

in with melted boots because they were walking on that hot metal. They were finding that the masks made it hard to work; it was hard to breathe with those masks on, so a lot of times they would just take them off.

My first shift there was eighteen hours, but it might have been longer because it took a long time for me to make a phone call to the guy who could come and relieve me since the phones weren't working at all. The second shift was longer. They eventually closed the office there and moved to Pier 92.

After 9/11, I was working for the 311 Call Center at 59 Maiden Lane, so I was still in the area, still finding pockets of debris and dust. The fumes from the pit were constant. It was always there, and you could smell it.

I didn't feel the upper respiratory stuff until later—years down the line. That's one of the worst effects that I got. My upper respiratory [system] is just shot. I started to notice that I would get sinus infections over and over again. At one point I was at a state where I couldn't sleep. Every time I heard a noise—I live in Brooklyn—or a rumble, I would have to get up and check it out. If there were planes overhead I would have to watch them and make sure they were headed towards the airport. And this was 24/7. If I talked to people about the incident, I would get these feelings of terror. For some reason it affected me really strongly, even though I didn't know anyone personally who was killed. At one point, I started to have panic attacks. Extreme panic attacks. These panic attacks would wake me up and I had never experienced anything like that before. I thought I was dying.

I think I saw a pamphlet for the Program [World Trade Center Health Program] at work, so I went. I remember the first set of questions they gave me... It must have been 2008, 2009. By the time I was at the bottom of the first page, I was crying because it seemed like they were zeroing in on everything that was really bothering me and I didn't realize it until I was done with the questionnaire. I realized then that I had a lot to work on. It became like my second job. I would go to work and then I would go there. There is a nurse in the Program that taught everyone very effective ways of getting into a meditative state, getting relaxed. I learned quite a bit about how to handle extreme emotions.

The upper respiratory issue is still bothering me. I have to be careful—mostly using the saline solution⁴ to keep my nasal passages moist. And I'm trying not to catch anything else. I just have to be careful. I think 9/11 exacerbated my depression. For me it got to the point that it was debilitating. I couldn't get my work done I couldn't get any sleep and that makes everything weird. You can't feel normal if you haven't got a night's sleep and then later on, it becomes a breaking point. I had to leave work for a few months of more intensive care. I am back to work now under the Program's care.

4. Saline solution is a general phrase referring to a solution of salt (sodium chloride) in purified water. There are many medical uses for saline solution, ranging from rehydration to wound care.

The fumes from the pit were constant. It was always there, and you could smell it.

MENTAL HEALTH CONDITIONS: PANIC DISORDER, MAJOR DEPRESSIVE DISORDER, ANXIETY DISORDER, MILD & MODERATE DEPRESSION – Comments of Alicia Hurtado, MD, Psychiatrist, Associate Medical Director of the World Trade Center Mental Health Program

RESPONDERS I TREAT commonly have mood disorders which include major depressive disorder, mild and moderate depression, anxiety, panic disorder, and generalized anxiety disorder. Major depressive disorder is a disorder in which sadness persists and lasts most of the day for weeks. Usually patients don't want to interact with their family members, and seem very irritable. They can experience other physical symptoms such as decreased appetite, abnormal sleep patterns, problems with their memory, and difficulty concentrating. Something particular to this population of patients is that they have demonstrated a tremendous amount of avoidance. Patients avoid their emotions and exhibit dissociation, which is when patients detach from reality. After getting to know the patient better, we often realize they don't necessarily have memory impairment but are using avoidance as a psychological way of defending and protecting themselves from things that were painful. We have had a few patients whose depression became so severe that they also had psychotic symptoms.

Panic disorder involves disabling episodes of panic that are ongoing and prevent the patient from being able to function. Patients often describe the panic as something that comes on out of nowhere. With treatment, patients start to learn that it is not something that comes out of nowhere, there's usually a trigger. For example, a lot of our patients have upper respiratory problems and acid reflux that can actually feel like panic. I've had patients who begin to feel short of breath because of their pulmonary problems and because they're anxious, they start to panic. It's very hard to treat because you have to train patients to tease out what is really asthma not anxiety. Sometimes one starts before the other and it's hard to identify which one came first. It's also tricky for us because sometimes our medications can worsen some of their pulmonary symptoms.

More and more now we're also seeing adjustment disorders, where patients had been functioning with some underlying anxiety but are now facing major life changes like retirement, developing cancer, chronic medical illness, or other major tragedy—that pushes them over the edge. For the general public, retirement is usually something to look forward to, but for many of our patients work was stabilizing—it allowed them to escape from their worries and was truly part of their identity. That identity

helped them continue to be strong and powerful, but when that's taken away they begin to feel weak and vulnerable. That weakness is actually what becomes anxiety invoking.

We are also now seeing that patients who have been mentally ill for years are having a difficult time reintegrating into the community. Some police officers tried to go back to work in private security but couldn't tolerate carrying weapons anymore. For other patients, they lacked the language skills to get office jobs. This limitation has now caused economic and social stress, additional stress in these patients' already stressed lives. Often their homes break up because their families can't tolerate the fact that they can't provide. Although it's something that is also frequent in the general population, it's unique for our patients in that they went from being heroes to being disabled. In the general population, when people have a vulnerability towards a mental illness they're often not as high functioning, but our patients have actually been very high functioning.

More and more we're seeing patients who can only maintain psychiatric stability by having ongoing treatment and medication management. Part of what we're trying to do now is figure out how we can help these patients move forward. One of the treatments is behavioral therapy, where we teach patients coping skills to help them tolerate interpersonal situations that may cause anxiety or help them change behaviors through talking. I have the luxury of treating patients long-term, which has made a very big difference in their treatment.

Other patients haven't been able to become independent because they have an underlying substance abuse problem, which requires long-term treatment and must be treated before we can help them.

Another new issue is that some of our patients are developing serious medical problems, like cancer. I've had more patients die these past 5 years as a psychiatrist than when I was a resident treating the general population. We've had to tailor our treatment to help our patients deal with end of life issues, like death anxiety. We've had to increase our training on how to cope with chronic medical illnesses and chronic pain.

The trauma that our patients were exposed to is different from many other types of trauma, like earthquakes or tsunamis. Those traumas are experienced as a community. Our patients' experience is more similar to that of a war veteran. They experience something very traumatic but when they go home no one else has experienced their trauma in the same way. It's very isolating and shameful. Studies have shown that individuals who can process trauma together have better recoveries. We have created such a community in our clinic. In our groups, responders work on their issues together, bond over their experiences and support each other. Their isolation starts to dissipate. It's great that something like this exists, and we need to continue to provide a space for this.

**Our
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war veteran.**

Paul Gerasimczyk

AGE: 56

OCCUPATION: Police Officer (New York Police Department)

CURRENT STATUS: Retired 2004

INVOLVEMENT IN 9/11 RESPONSE

EFFORTS: NYPD Rescue/Recovery



The day of 9/11 I was working with my partner. We were both assigned to the NYPD bus unit. We were directed to go to the World Trade Center off Vesey and Church Street. We parked the car opposite City Hall on one of the side streets, and we started to walk south on Broadway towards Vesey. We were by St. Paul's Chapel when the first building came down. I thought a small nuclear device had gone off because at this point I still didn't know it was an airliner that went into the building. It sounded like freight trains when the building collapsed. It became like a nuclear dawn. We made our way over to Chambers Street and Elk Street and I met up with a couple of detectives that I knew coming out of One Police Plaza⁵. The detectives explained what happened, that the planes had been hijacked. There was a lot of confusion. The radios went out because the master antenna was up on the World Trade Center towers. The radios were out for a long time. The cell phones were out as well.

We were wandering around the area, trying to get a fix on stuff. We had no real direction because the radios were out. We went to Manhattan Community College, which had an open side door and a bank of phones. All were dead except for one so we started making calls. We started leaving messages with people to find out what was going on. Then we went over by the West Side Highway to see what was going on and the firemen were sitting on the wall—on the Jersey barrier that splits the streets. There was a lot of damage to the buildings over there. You could hear the chirping of the firemen's body alarms; it sounded like crickets. It's an alarm that gives off a chirp when you're not moving or in trouble, so you could hear that. It was just a terrible, terrible afternoon.

That first day someone had gotten some paper masks from somewhere. I had lost my ability to see depth perception from the dust. We worked until midnight that night and then our Inspector dismissed us and gave us our orders for the

You could hear the chirping of the firemen's body alarms; it sounded like crickets.

5. One Police Plaza is NYPD Headquarters.

next day. We worked 4:00 a.m. to 4:00 p.m. shifts six days a week for weeks and months on end. I wasn't concerned about getting sick at the time.

There was no day to relax or pull yourself together, or get your body situated. Everybody was coughing up the stuff they inhaled kind of like black phlegm or they were blowing mucus out of their nose, which wasn't normal. Our clothes were saturated with the dust. Our skin—or my skin—got incredibly itchy from the asbestos and from the fiber glass in the air. I still have issues, skin issues, on my hands. It kind of kept increasing in severity. I had a pair of shoes, I am sorry I didn't keep them, but their soles just fell apart, they just deteriorated.

In 2004, I came to Mount Sinai and it has been very helpful to me. The doctor here, she was the first one that told me my coughing spells were asthma. At night, I would start coughing and coughing, and I would break out into little beads of sweat. She told me that I was having asthma attacks. Then I started getting all of the different tests, and they discovered I had Chronic Obstructive Pulmonary Disease (COPD) and Reactive Airways Dysfunction Syndrome (RADS). In 2007, they found a tumor in my kidney, which is recognized as one of the 9/11 illnesses. I had one third of my right kidney removed.

Then in 2009, the pulmonary staff here thought I was inhaling my own stomach acid and damaging my lungs from the Gastroesophageal Reflex Disease (GERD). I have GERD and I now have short-segment Barrett's Esophagus. I have moderate to severe sleep apnea. I wake up twenty six times per hour.

I also had back injuries. What happened was when we were running away from the buildings, my arm got weak. I just couldn't tense the muscles in my arm. I ended up going to the police surgeon for that. I still have problems with my back now. I am getting epidural injections in my spine, which I have been getting for ten years. I can't stand for that long. I am not working right now. I have a hard time walking up the stairs because my breathing has gotten worse and where I got the (kidney) surgery I can constantly feel it. I get pain in my abdomen when I stand too long. When I go out for errands, I have to cut it short. I can't spend a lot of time walking around or standing up.

The experience at Mount Sinai has been A-plus. It's great—everything from the doctors to the staff. I go to the group meditation therapy here and it's very good; it helps. I have been doing a lot of reading on meditation. It helps you relax and heal; it helps you not have any negative thoughts.

For me, it's a personal issue. I have my memories of the day. I can still see it right now, where I was, what I was doing. Everything else that has transpired since then—the families of people who got killed—it was terrible. They had children. They had wives. They had families left behind. The people that died afterwards from illnesses, they just suffered so much. And their families suffered

The people that died afterwards from illnesses, they just suffered so much. And their families suffered too.

too, through the treatment—through their physical pain. The two people who I worked with and were close to passed away. They were both in the Program. They died. There was nothing good about it. They suffered all the way to the end.

CANCER – Comments of Krzysztof Misiukiewicz, MD, Hematology and Medical Oncology

I TREAT MOSTLY head, neck and thyroid cancers, and initially lung cancer. Many patients suffered from lung cancer in the beginning of my time here. Some of them passed away and some are still alive. More and more now, it's mostly not newly diagnosed patients I see but mostly surveillance of those that were diagnosed in the past. I monitor patients that have already been diagnosed and treated for the lung cancer. When we complete the treatment, patients get scans every 4-6 months for the first few years. After 5 years they only require an annual exam with an x-ray or CT scan.

Right after 9/11, lung cancer was not one of the diseases approved to be covered by WTC funding so for some patients it was challenging, particularly if they didn't have secondary insurances. Now it is included, so it's easier. The funding covers the treatment and diagnosis but doesn't state that the development of the cancer was just because of exposure to fumes at WTC. It's difficult to say what the connection is because there's not such a test or a study available. I'm sure there's research being done but I'm not aware of any official reports.

In around 2010, 5 or 6 years ago, we saw a peak in cancer in this population. It's hard to say whether the numbers I'm giving you represent what is actually happening because they may have been seeing other outside physicians and oncologists before this time.

Many patients were smokers or had direct asbestos exposure, which can contribute to head, neck and lung cancer. The 9/11 exposure is another factor that may contribute to the development of cancer. There was a lot of exposure because there were problems with quality standards of masks. This exposure may have an additive affect with smoking or asbestos, so we may see the number of responders with cancer increasing. It's hard to say what other cancers we will see because there were many chemicals up in the air during 9/11.

I feel it's a burden for these responders because obviously they went down to WTC to help and now they suffer from complications. For me, it's very rewarding to help them.

Placido D. Perez

AGE: 58

OCCUPATION: EMS/Telecom

Engineering Manager

CURRENT STATUS: Retired

INVOLVEMENT IN 9/11 RESPONSE

EFFORTS: Emergency Medical Services
(EMS) Volunteer



At that time, I was a licensed EMT in Matawan, New Jersey. I worked in New York City as a senior customer support manager in telecommunications. I worked for a company called Global Crossings over at 88 Pine Street. My commute everyday was from Matawan, New Jersey. On the day of 9/11, I arrived on my normal commute to the WTC from the PATH train at about ten past eight in the morning. The PATH train pulled in at the lower level. I proceeded to go upstairs and that day the Hudson newsstands throughout the WTC were closed. I didn't think anything of it. I stopped to get a coffee in the concourse level and as I proceeded out towards Chambers Street at around 8:40 a.m. I heard this loud sound like an engine, squealing like a jet engine, and then I heard an explosion and that's when the tower was hit. I had a camera on me, because I always had a camera—we used to do site surveys for big corporations. I started taking pictures of the towers. These photos that I have, I have never sold for any profit.

It felt like an earthquake; all you could hear was a grumbling. Everyone was running away from the site. The day when it happened, I was concentrated on just getting out of the city. I spent the whole day trying to leave.

The next day, I came back to the site. I volunteered my services. All first responders and volunteers met at the Jacob Javitz Center area and were transported via special MTA NYC buses to the Stuyvesant High School location. From Stuyvesant High School we walked south on the Westside Highway to the American Express building located at the World Financial Center, which was set up as a temporary Command Center at Ground Zero. Inside the lobby of the American Express building there was an area set up with food, water, cookies, and other food items, which were all donated. Another area was set up with supplies: filters for respirators, flashlights, shovels, picks, buckets, ropes, gloves, and much more.

We had respirators, or masks, and we changed our filters every six hours, except when we were eating. When we were eating, we had to take the masks

off. I don't know who was giving them out but firefighters, police officers, and EMS workers had their own equipment.

The steelworkers were cutting steel beams from the walk bridge over the Westside Highway in sections; these needed to be removed so they wouldn't collapse on us. They were cutting sections of the walk bridge and putting them on trucks. They had all these trucks on the West Side Highway, where they would load everything and bring it to the Staten Island Dump location to drop off the debris. At different intervals, I had my small little digital camera and would take photos here and there while I was doing my job. I did various things. We did triage inside the American Express Building—putting in eye drops for firefighters and police officers and treating all sorts of injuries, scrapes or anything. When we weren't doing that, we were out helping with the bucket brigade. I stayed on the site until the 18th. We did twelve, thirteen, fourteen-hour shifts and then rested, sometimes in the American Express building. Other times we would go back to the Stuyvesant High School.

Then around 2005, 2006, I started getting sick—started getting panic anxiety attacks and a lot of respiratory problems. The back of my throat and nose area would burn. I also had a lot of problems where I would choke in my sleep because I had some sort of acid reflux taking place. Then I found out about the Program and started getting treatment. I have been with the Program since 2007. I was diagnosed with GERD, restrictive lung disease and severe rhinitis. It was six years after the attacks. I didn't know these were related to 9/11.

Then there's the mental health side. I was having a lot of panic attacks. I went to the emergency room numerous times thinking I was having a heart attack but then I would be cleared from a cardiac standpoint. Thank God for the Program; from a mental health standpoint it has helped a lot. It helps me understand that I am not having heart attacks; it's mostly anxiety and anxiety is a killer. PTSD can kill you. Thank God for anxiety medication.

After 9/11 my company filed for Chapter 11 and went out of business. After I lost my job, they gave me a severance package since there was no work available. I couldn't find any jobs in telecommunications. I lost my apartment in New Jersey because I didn't have a job and I was living on my savings. When I exhausted my savings, I moved in with my brother. Afterwards I did some armed security work for high profile corporate companies. It got difficult though because it was a high stress job and I started getting sick with the panic attacks and acid reflux problems. I had to leave my job from security because of that. I haven't worked in five or six years because of my conditions. I also didn't have medical insurance at the time because whatever I got from the severance package was limited insurance. I couldn't afford the COBRA payments. The WTC Medical Monitoring program is God sent; the issues can take a big toll on you.

I want people to know—to all the responders out there—thank you. I would do it again in a heartbeat if it happened again. This Program is tremendous. People who are sick and who were there should seek the help they need.

**I would do
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again.**

MENTAL HEALTH CONDITION: POSTTRAUMATIC STRESS DISORDER (PTSD) – Comments of Kathryn Marrone, LCSWR, Assistant Director of Mount Sinai Social Work

POSTTRAUMATIC STRESS DISORDER (PTSD) is a condition that can occur after experiencing a traumatic event and may include symptoms such as flashbacks and nightmares. A flashback, unlike just a memory, is when a patient truly feels that they're back in the situation they were in during the trauma. For example, some patients describe that there are moments they feel they can see the pile in front of them again. Other patients describe smells, like from hot dog vendors that trigger flashbacks of the pile. This can be terrifying for patients. There are many triggers all over New York City that can affect our patients so much so that many of them end up moving to get away from the ongoing reminders.

Even if a patient experienced a different form of trauma in their life, 9/11 affected most on a larger scale. Unfortunately many responders didn't originally reach out for help because there is often a stigma attached to PTSD or other mental health issue. Yet, the longer they waited, the more difficult it became to treat because of the additional stressors that contributed to their symptoms over time, including social problems like a dissolving marriage or job as well as chronic physical health conditions.

9/11 has taken a big toll on the responders' family life. Family frustration is one of the most prevalent topics that we hear about. We see a lot of difficulty in marriages. Responders' children struggle with what they felt was an absent parent or a sick parent. Most of our patients express that they don't talk to their spouses about the issues they suffer from, so we help them engage with their spouses. One of the biggest complaints we get from spouses is snoring from obstructive sleep apnea. They're already disconnected with their partner emotionally but now they also sleep in different rooms because of the snoring, causing further disconnect. Quite a number of patients with PTSD may also wake spouses up with nightmares. All of these issues come together to create the perfect storm for marital discord.

Today, we see that chronic health issues that have developed since 9/11 have had such a huge impact on mental health issues. Many patients are still searching for an older version of their life that doesn't exist anymore. Patients can't erase the trauma or pretend it didn't happen. We try to help patients understand how the trauma has changed them and what they can do to adapt.

9/11 has taken a big toll on the responders' family life.

MENTAL HEALTH CONDITION: POSTTRAUMATIC STRESS DISORDER (PTSD) –

Comments of Mickie Brown, RN, HN-BC, Deputy Nurse Manager Selikoff
Centers for Occupational Health

THE PATIENTS COME to the WTC monitoring clinic for a yearly exam designed to assess physical and mental health status associated with WTC exposures. At this time, the nurse takes an extensive health history. It is this health history that provides the data for the epidemiological study as well as providing valuable information for the physician or nurse practitioner for the patient assessment. It is during this time that many patients express their vulnerability and divulge personal information they have never shared before. This affords the nurse the opportunity to encourage patients to seek mental health counseling in our highly confidential setting and to allay fears around physical health.

The fear of cancer is pervasive in our patients as they impotently watch when fellow responders are diagnosed or die from cancer. Information is a powerful way to diffuse this fear and the WTC nurses have developed a commendable library of patient information packets. Each nurse has become a specialist in a health area and has researched various sources to find the best, most accessible information for each patient. Florence Nightingale said, “Apprehension, uncertainty, waiting, expectation, fear of surprise, do a patient more harm than any exertion.” The goal of our nursing staff is to provide information, guidance and motivation to empower the patient to adopt health habits that will directly affect immune functioning and health outcomes.

I personally became very interested in mind body medicine when I was taking the health histories of our patients shortly after joining the WTC Program as a nurse. I found that patients felt so powerless and anxious. I knew enough about the physiology of the breath and felt I could teach my patients to use it to calm themselves. I attended the Center for Mind Body Medicine to become certified in Mind Body Medicine and with permission of the Medical Director, started a stress reduction program using several ancient practices including Mindfulness. By providing them with some tools, they could feel empowered, relaxed and calmer, which of course would have an effect upon their overall health.

As clinicians, we’re here to support our patients and provide them with the means to do what they need. I really love having this skill to teach them because it makes such a difference for so many of them. If you can help them to change their lifestyle and their reaction to stress, you’ve given them a really powerful gift. There is hope for some of these people that are so sick and it should be celebrated.

**There is
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Deidra Maxwell

AGE: 64

OCCUPATION: Supervisor

Highway Repairer

CURRENT STATUS: Retired

INVOLVEMENT IN 9/11 RESPONSE

EFFORTS: Supervised Debris Removal



I was a supervisor at the time and when the towers fell I was out on workers' compensation. I had knee surgery, so I missed the initial wave of it that day. My agency was definitely involved in the response; I worked for the highway department, Department of Transportation (DOT). I was down there from November until April for the cleanup. I supervised the men in the trucks that were taking the debris to the barge on the West Side Highway. I kept a record of their times and made sure that they were diligently doing their jobs as much as I could. It was one of the most harrowing experiences of my life. It was indescribably morbid. The cleanup took forever. One of the things I remember so vividly is that every time they found a body, a silence came over the whole workplace—everything stood still because of the bodies they were still finding. In November, they were still finding bodies.

There was nothing to prepare you for what happened. As far as safety goes, there was nothing because all you could do at the time was respond and try to make a difference. You couldn't think about all that. You just wanted to help somebody. Everybody I knew had the same initial reaction to just respond as opposed to thinking of their own safety first. This was not about safety, it was about thinking, "maybe I can make a difference; maybe I can help somebody." I think the human element kicked in more than anything else. I was down there and I was alone going from point A to point B, but there was interaction in the tent when it was time to eat. I remember we had to wash our feet, like that was going to do something, but all it did was supposedly prevent us from tracking the debris that was out there into the tent so that the tent could be a safe environment for us. But being down there, you could hear the people crying.

I have never been on any type of medication. I am an upbeat person, love-living enjoy-life type of kid; I'm a flower child coming from the 60's and the 70's. When I retired, I had a breakdown on the anniversary and just cried and cried because I had to face it; I had to face what I had to live through, and I

had to go seek help for the first time in my life because I wasn't functioning. I was so depressed. I had never addressed what happened. I just did it because it was the right thing to do; I just did it because it was my job. I just did it and I did not allow myself the privilege of breaking down; I just kept going. I sought help but I could not identify with the therapist—it was the first time I had ever went for therapy and the young lady didn't have a clue what I felt and what I was talking about. Then I found Mount Sinai through the monitoring program and I inquired about mental health treatment.

Mount Sinai has been geared to help and the people who work here have a level of empathy with the people who come. I think they see the sadness that we all have, because there's a lot of sadness with responders. When I first went to group therapy, there were things that I thought only I was experiencing. I found out that others were also experiencing the same things. We were all trying to fill a void and we couldn't explain what was going on with us. We all had limited functions with our families. We were all angry. I would go shopping trying to fill a void and I found out someone else did the same thing. I knew I wasn't unique and it helped me identify the fact that something was wrong.

My breathing has gotten very bad since being down there and I protected myself as much as I could. I didn't wear a mask or anything but I stayed in the vehicle I was in as much as I could. Still, there was no running from what was there. I was diagnosed with seasonal asthma before 9/11 but now I have "real" asthma. I am on two different pumps and I have allergies more so now than ever. I try to monitor my environment. I try to pay attention more than ever to my triggers. I try to create a safe environment so I can live the best quality of life that I can. I can't walk around with a bubble around me, but I can know that smoking triggers my asthma and I try to stay out of environments with a lot of cigarette smoke. It's just the awareness I have been given coming to this monitoring program.

I am more health conscious than I have ever been. When I started therapy, one of the things that helped me mentally was picturing the people that passed down there, living vicariously through me. It gave me such a greater appreciation for life. It really did. It gave me such gratitude for the life I had, because I was capable of having empathy for not only the people who passed but for the families they would never come home to.

Grief is something—I didn't realize until 9/11—that you feel whether or not the person is part of your family or network. Grief is grief. A loss is a loss. If you're not affected by it, then you need to check your humanity. It affected me very, very badly. Mine was not as physical as some people's because I dodged the bullet by not being down there on the day of September 11th, but believe me if I had been scheduled to work, I would have done my job.

One of the things that I subscribe to is that when things happen to us,

**I just did it
because it
was the right
thing to do;
I just did it
because it
was my job.**

things happen for us. My value of life is completely different. I started seeing life through different eyes. I am at peace. For the first time in my life, I am not living for anybody else, not living for anyone else's expectations of me. That is such a blessing to be able to just be me.

ASTHMA – Comments of Michael Crane, MD, MPH, Occupational and Preventative Medicine, Medical Director World Trade Center Health Program Clinical Center at Mount Sinai

INITIALLY, RESPONDERS INHALED a bunch of material down at ground zero. It was so irritating to them that they coughed it up constantly. This acute bronchitis stayed and became chronic, and that chronic irritation now often becomes asthma.

There's a lurking concern among many of us that we don't yet have the whole story about lung disease in this population. We keep hearing "I can't catch my breath" or "I'm winded" but the nagging concern is there that this other type of illness that we're not really prepared for yet may emerge in this population. It's really one of the reasons why we need to watch these patients long term, and is really one of the reasons why the Zadroga Act really has to be reauthorized so we can keep an eye on this going forward. We worry about the length of time that we need to follow patients to truly assess the impact of their 9/11 exposures. In the 60s, Dr. Selikoff did extraordinary work on asbestos that showed how asbestos-related illness can hit people even 40 years after initial exposure. This may be true of 9/11 exposure induced lung disease as well. So the long term is really what's important here.

ASTHMA – Comments of Laura Crowley, MD, Occupational, Pulmonary, and Internal Medicine, Deputy Director World Trade Center Health Program Clinical Center at Mount Sinai

ASTHMA IS INFLAMMATION and constriction of the airways. Patients tend to notice that they develop shortness of breath, wheezing, tightness in their chest, and coughing, which is not just during the day but also may occur at night. Patients may also have other World Trade Center illnesses as well including GERD and upper respiratory issues like rhinitis and sinusitis.

Asthma symptoms tend to develop in the setting of particular triggers like smoke, dust in the workplace, certain chemicals, allergens, or pets. I think what makes the responders' asthma unique is the fact that they had this exposure and they're still dealing with this illness so many years out after the event.

Asthma is a reversible disease that can be treated with inhalers. However, treatment is something patients need to be educated about so they know what kind of triggers to stay away from and how to be compliant with their medications. We need to continue to monitor, and take care of these patients. We feel very strongly that this is a cohort that should continue to

There's a lurking concern among many of us that we don't yet have the whole story about lung disease in this population."

have close follow up and health care access through the Program by physicians who really understand the management needed and recognize the idea that WTC exposure has contributed to the development of WTC-related asthma as well as other lung diseases.

ASTHMA – Comments of Jessica Silverstein, FNP-BC, Clinical Program Manager Selikoff Centers for Occupational Health

WE USE PULMONARY function testing (PFT) and a methacholine challenge to help us diagnose asthma. PFTs give us a picture of how well the lungs are functioning and in some cases may show a bronchodilator response, which in most cases confirms a diagnosis of asthma. The PFT uses patient's BMI, gender, race, and smoking history to compare patient results with normal values. The methacholine challenge tests for airway reactivity by exposing the patient to an agent that may trigger asthmatic symptoms.

In some cases, people are asthmatic as children but grow out of it in their adolescent years. Some of my patients had asthma as a child that redeveloped after their 9/11 exposure. Some of these patients also have poorly controlled upper airway disease and reflux that makes their asthma more difficult to treat.

Many of our patients have severe asthma that requires multiple steroid courses per year. Long term steroid use can potentially increase the risk of developing type 2 diabetes, weight gain, and osteoporosis amongst other things, which is concerning.

Richard Dixon

AGE: 49

OCCUPATION: POLICE OFFICER
(New York Police Department-Transit
District 11-Bronx)

CURRENT STATUS: Full-Time

INVOLVEMENT IN 9/11 RESPONSE

EFFORTS: NYPD Rescue/Recovery



When the first call came in, I was dropping my young son off at school, and on the TV it was showing the planes crashing. Then I came home and saw it on the news and the city started mobilizing so we all had to proceed into work. When there's that level of mobilization it pretty much means everyone is going into work. I did go into work that day. When we got to work, we stayed within the commands. We started setting up perimeters and pretty much that's when the tours started working around the clock. The next day a group of us went down to the WTC site on our own time after work.

I was part of the bucket brigade. It was very impressive how everyone fell in without being told what to do. There were different brigades all over the place. At that point we didn't have masks so we were sucking in all the dust. You could feel it. But you didn't think about it. We didn't look days, weeks, or months down the line. It was basically get your hands dirty, find anything you could.

I put a lot of hours in. We were sent down during work and after work. I was there off and on for the first four to six months. We didn't think about it; we just did it. We just went down and we dug. It was just so unreal; we didn't process what was happening. We just did it and went home. I still have my shovel that I used, which was provided by NYPD, and my helmet that I used. It's in the closet at home. Not as a souvenir, but as a reminder.

How many times did they tell us it was safe? "Don't worry everything is safe. You can do what you got to do." And then all of a sudden they said it was a toxic mess. For most of us when we hear that it's safe, we're not going to think twice about it. We're just going to do our job. It was hot down there and you would take off your mask and then you would get dust in it not realizing what it was. I don't know how many times I had the mask down not knowing the importance of it. You'd think we'd know this, but we didn't realize how much damage was done by sucking in that dust. You'd bring those clothes home not realizing what you were bringing home and throw it into the laundry basket contaminating

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safe?**

everything else. It was just unknown. Today, I think it would be different because of what happened back then. If I had to respond to something like that again—I know the dust is not good and I would not just throw my clothes in the everyday basket with the rest of my family's stuff.

I started this Program [Mt. Sinai-WTC Health Program] a few years after 9/11. I did the yearly medical monitoring. I haven't, thank God, been diagnosed with anything major, just a little sleep apnea, which they take care of here, and sinusitis, which they provide the medications for here. The GERD, which I had never had before, was very bad in the beginning but what I take here has settled everything down to a normal stage. It's manageable. Without the Program here, the conditions probably would not have been manageable. Sleep apnea is one of the big ones for me; I never knew why I was tired during the day. But then when they found it, the quality of life has changed. I wear the CPAP mask every night. Now I can go from morning to night without that exhausting feeling.

A lot of the people I worked with have retired—throughout the years as time has gone on—I have lost quite a few friends at a young age. Most of them are 9/11-related. I'm seeing all these different cancers that are coming up. I'm talking people in their late 40s, and early 50s. It's such a young age group acquiring these conditions; it's just not normal. There are just so many getting lung diseases and cancers, every time I look in the paper these days or on social media, I see someone else has passed away.

What needs to be heard today is that there are ramifications that are still coming from that day. You know I am 49 years old; I was in my mid-30s during that time. A lot of the department was around that age and now so many young people that I know personally—have worked side by side with—are dying in their 40s and 50s of these different cancers. There's just no need. That's what cannot be forgotten. I don't want to become part of that statistic.

People say never forget but they do forget. But hopefully this Program won't forget. It doesn't matter what everyone on the outside thinks, what matters is that the Program here doesn't forget and that people who need it are here.

OBSTRUCTIVE SLEEP APNEA (OSA) CONDITION – Comments of Adam Hernandez, MD, Pulmonary Disease, Critical Care and Sleep Medicine

ALTHOUGH I SEE all sleep disorders, the vast majority of what I see is obstructive sleep apnea (OSA). OSA involves repeated episodes of blockage of the upper airway during sleep. The real site of obstruction in sleep apnea is the posterior pharynx, the area well behind the tongue. The apneic episodes, which are short term pauses in breathing, typically last from 10 seconds up to even 2 minutes. Your brain will then arouse and you'll start breathing again.

When the obstructive sleep apnea is moderate to severe it's associated with symptoms like day time sleepiness, unrefreshing sleep, and an overall poor quality of sleep. Obstructive sleep apnea may be associated with pulmonary diseases. It is certainly associated with a significantly increased risk of cardiovascular disease as there's a very strong association between untreated obstructive sleep apnea and heart attack. Treating sleep apnea reduces high blood pressure and prevents recurrence of atrial fibrillation. We do not yet have data that says if you treat sleep apnea you can prevent heart attacks though. We're still waiting on answers.

It seems to me that there is a very high prevalence of obstructive sleep apnea in this population of patients but also in the general population. It remains unclear how it's truly related to 9/11, except for the fact that a lot of WTC patients have so many of the risk factors for obstructive sleep apnea. These risk factors include: obesity, male sex, high blood pressure, age, increased neck circumference, and snoring.

The primary treatment is Continuous Positive Airway Pressure (CPAP) therapy. This involves putting on a mask at night that relieves the upper airway obstruction. CPAP is the perfect example of a treatment that's efficacious— in laboratory studies it has resolved almost all sleep apnea—but not very effective in patients. Patients have a low ability to tolerate it with approximately 50% of patients having trouble wearing the mask. Other treatments include oral appliances and surgeries but they don't work as well with severe sleep apnea. CPAP is most effective with just a nasal mask as opposed to a full face mask which covers the mouth. Although there's not a well-known risk factor of nasal problems worsening sleep apnea, I wouldn't be surprised if it were studied and they found that patients with nasal problems, like chronic sinusitis and rhinitis, did have a lower rate of adherence to CPAP because it may make it more difficult to wear the CPAP mask.

Some patients may suffer from insomnia, which most directly stands out in my mind as a WTC-related issue from the psychological trauma

these patients have endured. There are various things that can contribute to insomnia, like depression, anxiety or panic disorder. Many patients had normal sleep patterns but after experiencing 9/11, developed acute insomnia. For some patients, their insomnia resolved. In other patients, though, it just sort of took on a life of its own and became chronic insomnia. Chronic insomnia includes prolonged difficulty initiating sleep, maintaining sleep, or waking up too early in the morning. Many of my patients have developed this chronic insomnia that hasn't resolved over a decade after 9/11.

Many of my patients have developed this chronic insomnia that hasn't resolved over a decade after 9/11.

Haydee Diaz

AGE: 51

OCCUPATION: Actor

CURRENT STATUS: Semi-retired

INVOLVEMENT IN 9/11 RESPONSE

EFFORTS: Flagger; member of

LIUNA Local Laborers 731



My friends and I worked from seven in the morning till seven in the evening. We were given a clipboard and we manifested the debris trucks exiting the site. Some of the debris trucks were for steel and others were for regular debris-nonferrous. We dispatched them to their respective piers depending on what they were hauling. My co-workers and I would do this six nights a week. I started at the end of November until the first week of June, the next year.

I became unionized while I was down there because they had me do traffic control as opposed to what I used to do, which was manifesting. Once you do a union job, you have to become a union member. I joined and I was in the union for another year, maybe year and a half. My title was a flagger which was essential work since traffic control was absolutely necessary. There was entering and exiting traffic along with interior and exterior traffic. It never stopped. Flaggers were vital in maintaining order otherwise it would have been chaotic.

At first there was nothing in regards to safety and protective gear, it was just the clipboard and we were told to just go out and do it. One night they told us all that we had to take a safety class. It was maybe one or two months in. In the class, they told us that we had to make sure to wear our respirators, boots, safety glasses, and hardhats and they told us about the importance of washing our hands all the time. In the beginning we had everything but the respirators and at some point—don't remember when—respirators were distributed, but by then it was too late. Here is the thing. We had to climb up on the trucks while the driver was idling and get their information: name, company, time, what your load was, etcetera. We tried to do this with the respirators on but they couldn't hear us with the inordinate amount of noise going on there with all the machinery. We were pressured to get the line rolling because there was a certain amount of round trips that needed to get done and we were pretty good at it. We really excelled. So we ended up taking off the respirators and letting them hang. Once you take it off and dust gets in, which we learned in union-taught safety class about over a year later, we then realized it was useless.

I did feel a cough and a tingling in my throat but I forged on, maybe it was adrenaline. But I didn't really feel it was life or death until much later. Like maybe two to three years later, I still thought it was just everyday shortness of breath. I didn't have insurance to see a physician and then one day at the union, I saw a flyer that said if you feel any of these symptoms such as shortness of breath then go to Mount Sinai where they have the WTC Health Program and they can help you. I thought I should probably go over there because it didn't seem like my cough was getting any better. It was about February 2005 when I became part of the Program.

A lot has changed. My lungs have incrementally gotten worse and worse. I have had three nose operations for polyps; I lost the sense of smell a long time ago. It has been a lot. I never had stomach problems and now I have to take medication every day for the GERD, for the hiatal hernia, for the gastritis, which I have been to the emergency room for four or five times. The list goes on and on, and I don't know where I would be without this Program. I was uninsured and unemployed and I desperately needed medical help and they welcomed me with open arms. I have Reactive airways dysfunction syndrome RADS, bronchitis, sinusitis, allergic rhinitis, the gastrointestinal issue-GERD. My voice has changed throughout the years; it's always this dry cough. It's ongoing and there are many medicines that I have to take on a daily basis just to leave the house.

These conditions have affected everything. At this age, most of my peers are in relationships, have jobs, have children, and are maybe not in the best of health but they're doing fine. When we get together it's like I am the one with the bad news all the time. I don't work full time, I can't anymore, but I stay busy. Without these conditions, I believe I would have what I always dreamed of having—a more stable life, a career. I would be more independent than I am now because I live with family and I cannot afford to live on my own. It's like internally I am older than I really am.

But I would do it again in a minute. It's the best job I have ever had and the worst job. I felt like I was doing something, like I was doing something for New York, for us. Would I have done it differently? Of course. Hindsight is always 20/20. Hopefully I would have gained more knowledge by taking more classes.

I live in New Jersey and I take three trains in and three trains out and it takes about two hours. It says a lot about the Program that I would travel two hours and take three trains to get here. I don't know anyone else or any other entity that I would do that for.

These conditions have affected everything. It's like internally I am older than I really am.

CHRONIC SINUSITIS & CHRONIC RHINITIS –

Comments of Fred Lin, MD, Otolaryngology – Head and Neck Surgery

I TREAT PATIENTS with chronic sinusitis, chronic rhinitis, chronic nasal inflammation, congestion, stuffiness, and general discomfort. Chronic sinusitis and rhinitis are conditions in which the nasal and sinus cavities are inflamed, which can lead to chronic infections and problems with drainage. A wide range of nasal issues can also lead to throat and lung issues because of drainage back into the throat and down into the lungs. We don't really know for sure how the exposure caused the sinusitis or rhinitis. However, we think that it's possible that the high concentration of particulate matter and irritants in the air that people were breathing at WTC caused a response within their systems that created inflammation. For some reason they have maintained that level of chronic inflammation that we see day to day and year to year in this patient population.

The signs and symptoms of rhinitis and sinusitis in these patients have not abated in this patient population over time. We've treated these symptoms with medications like long term antihistamines, and anti-inflammatories as well as surgeries, but despite these therapies we still see persistent chronic rhinitis and sinusitis. In addition, a lot of the disease today in WTC patients is more severe and more symptomatic than the general population suffering from the same diseases.

For a chronic sinusitis patient, surgery is a last resort, often performed when medications no longer help and their day to day quality of life is severely affected. Surgery aims to help patients improve their chronic infections, prevent chronic pulmonary infections that stem from sinus infections driven down to the lungs, and improve their quality of life. Chronic rhinitis patients can have significant nasal obstruction, congestion, and stuffiness. These patients undergo nasal airway surgery to improve their nasal airway and allow them to breathe with improved functionality. We perform these surgeries to get them back to more normal lifestyles where they can actually breathe and not feel chronic congestion.

The most common symptoms of chronic sinusitis and rhinitis are chronic nasal and upper airway congestion with drainage, but they can also include associated symptoms like chronic infection, laryngeal reflux, polyps, voice changes, and malignancies. Sleep apnea is also very common.

All of these related conditions are truly a constellation of symptoms that follow the pathway of exposure of irritants at the WTC site to the upper airways. The nasal mucosa, or tissue, tends to be particularly sensitive, which is why we see a lot of nasal issues, but patients may suffer from conditions

The signs and symptoms of rhinitis and sinusitis in these patients have not abated in this patient population over time.

affecting anything from the nose to the mouth to the throat to the lung, which is why we monitor them so closely.

Another reason to monitor these patients closely is the possible increased risk of malignancy. Chronic inflammation may lead to a higher risk of malignancy over time so it is imperative that we have long term monitoring of this patient population. It's been a relatively short period of time for malignancies to grow, so it's something that may evolve and must be watched.

Many of these patients suffer dramatically; they come in to the office in absolute misery. Imagine yourself living with a severe cold 24 hours a day 365 days a year for years. It truly takes away from their quality of life. These patients put their lives on the line to help in a time of need and I think it's our duty to make sure that they're treated properly and have a reasonable quality of life now and for the future.

AFTERWORD

There are currently 72,395 responders and survivors in the World Trade Center Health Program⁶, living across all 50 states⁷. There have been over 11,000 new members enrolled in the Program since the passage of the James Zadroga Act in 2011, with more enrolling each month⁸. The responder and survivor population is experiencing new diagnoses of 9/11-related condition each year and as of recently there are 3,700 responders and survivors who have been certified with a 9/11-related condition⁹. Moreover, over 33,000 responders and survivors have one 9/11-related condition and about two thirds of the population are suffering from more than one 9/11-related condition¹⁰. More New York Police Department officers have died in the aftermath of 9/11 from their 9/11 illnesses than on the day of the disaster.¹¹

These statistics and the stories presented in this booklet speak to the magnitude of the enduring presence of the post-9/11 aftermath within this responder and survivor community and the absolute necessity of long-term medical care for this population. These stories are powerful illustrations of the ways in which responders have been personally impacted, heightening our understanding of the depth and complexity of post-9/11 repercussions from the responders' unique and central standpoint. The comments provided by physicians and medical providers at Icahn School of Medicine at Mount Sinai of Medicine, one of the Clinical Centers for Excellence within the WTC Health Program, allow us to recognize how these 9/11-related illnesses have evolved over time and will continue to evolve years into the future. This report provides a platform where responders' voices, their injuries, illnesses, and experiences are examined; and their hardships—even years after the disaster—are made visible. Healthcare for this community, and all communities impacted by 9/11, must continue to be a priority for our city and our country.

6. WTC Health Program- Annual Status as of 6/30/2015 (2015, June 30). In WTC Health Program. Retrieved from www.cdc.gov/wtc

7. World Trade Center Health Program Membership by State August 2014 (2014, August). In Citizens for the Extension of the James Zadroga Act. Retrieved from <http://www.renew911health.org/world-trade-center-health-program-membership-by-state-august-2014/>

8. WTC Health Program - Annual Status as of 6/30/2015 (2015, June 30). In WTC Health Program. Retrieved from www.cdc.gov/wtc

9. WTC Health Program At A Glance (May 2015). In WTC Health Program. Retrieved from www.cdc.gov/wtc

10. Ibid.

11. Memorial 9/11 Tribute (2015). In New York Police Department. Retrieved from http://www.nyc.gov/html/nypd/html/memorial/memorial_wtc.shtml

List of Currently Covered Conditions under the World Trade Center Health Program

THIS LIST OF conditions may be amended by the WTC Health Program Administer at the National Institute of Safety and Health (NIOSH) to include other health conditions if research reveals that they may be related to exposures from the 9/11 disaster. The Program may provide health care for conditions that are not on the list if they resulted from the treatment or progression of an underlying certified WTC-related health condition. For more information, call 1-888-982-4748.

AERODIGESTIVE DISORDERS

(Airways and Digestive Disorders)

- Asthma
- Chronic cough syndrome
- Chronic laryngitis
- Chronic nasopharyngitis
- Chronic respiratory disorder-fumes/vapors
- Chronic rhinosinusitis
- Gastroesophageal reflux disorder (GERD)
- Interstitial lung diseases
- Reactive airways dysfunction syndrome (RADS)
- Sleep apnea exacerbated by or related to another condition described in the list of aerodigestive disorders
- Upper airway hyperreactivity
- WTC-exacerbated chronic obstructive pulmonary disease (COPD)

CANCERS

- Childhood Cancers
- Any type of cancer diagnosed in a person less than 20 years of age.

MALIGNANT NEOPLASMS

- Blood and Lymphoid Tissue
- Diffuse Non-Hodgkin lymphoma
- Follicular [nodular! Non-Hodgkin lymphoma
- Hodgkin's disease
- Leukemia of unspecified cell type
- Lymphoid leukemia
- Malignant immunoproliferative diseases
- Monocytic leukemia
- Multiple myeloma and malignant plasma cell neoplasms
- Myeloid leukemia
- Other and unspecified malignant neoplasms of lymphoid, hematopoietic and related tissue
- Other and unspecified types of non-Hodgkin lymphoma
- Other leukemias of specified cell type
- Peripheral and cutaneous T-cell lymphomas

DIGESTIVE SYSTEM

- Colon
- Esophagus
- Liver and intrahepatic bile ducts
- Other and ill-defined digestive organs
- Rectosigmoid digestive organs
- Rectosigmoid junction
- Rectum
- Retroperitoneum and peritoneum
- Stomach

EYE AND ORBIT

- Eye and adnexa

FEMALE

- Breast
- Ovary

HEAD AND NECK

- Accessory sinuses
- Base of tongue
- Floor of mouth
- Gum
- Hypopharynx
- Larynx
- Lip
- Nasal cavity
- Nasopharynx
- Oropharynx
- Other and ill-defined conditions in the lip, oral cavity, and pharynx
- Other and unspecified major salivary glands
- Other and unspecified parts of mouth
- Other and unspecified parts of tongue
- Palate
- Parotid gland
- Piriform sinus
- Tonsil

RESPIRATORY SYSTEM

- Bronchus, lung, trachea
- Heart mediastinum and pleura
- Other and ill-defined sites in the respiratory system & intrathoracic organs

SKIN (MELANOMA AND NON-MELANOMA)

- Malignant melanoma of skin
- Other malignant neoplasms of skin
- Scrotum

SOFT TISSUE

- Other connective and soft tissue
- Peripheral nerves and autonomic nervous system

THYROID

- Thyroid gland

URINARY SYSTEM

- Bladder
- Kidney except renal pelvis
- Other and unspecified urinary organs
- Prostate
- Renal pelvis
- Ureter

MESOTHELIOMA

- Mesothelioma

RARE CANCERS

The following are considered covered under the rare cancer category:

- Adrenal
- Brain
- Central Nervous System
- Gallbladder/Biliary Tract
- Gastrointestinal Stromal
- Invasive cervical
- Male Breast
- Neuroendocrine
- Pancreas
- Penis or Testis
- Small Intestine
- Thymus

MENTAL HEALTH CONDITIONS

- Acute stress disorder
- Adjustment disorder
- Anxiety disorder (not otherwise specified)
- Depression (not otherwise specified)
- Dysthymic disorder
- Generalized anxiety disorder
- Major depressive disorder
- Panic disorder
- Post-traumatic stress disorder (PTSD)
- Substance abuse

MUSCULOSKELETAL DISORDERS

The WTC Health Program covers the following specific musculoskeletal disorders in certain situations if they were caused by your 9/11 work and you have proof that you received medical care for that injury on or before September 11, 2003.

- Carpal Tunnel syndrome (CTS)
- Low Back Pain
- Other musculoskeletal disorder

WORLD TRADE CENTER HEALTH PROGRAM

If this is an emergency, please call 911.

MAIN CONTACT INFORMATION

| | |
|---------------------------------|--|
| Call Toll-Free Telephone Number | 888-982-4748 (M-F, 9:00 a.m.-5:00 p.m. EST) |
| Email Address | WTC@cdc.gov |
| Website | www.cdc.gov/wtc |

CLINICAL CENTERS OF EXCELLENCE

WTC RESPONDERS

| | |
|--|------------------------|
| Icahn School of Medicine at Mount Sinai | 212-241-1554 |
| New York University School of Medicine | 212-263-7335 |
| North Shore- LIJ Health System | 718-267-2420 |
| Rutgers University | 848-445-0123; Option 3 |
| State University of New York, Stony Brook | 631-855-1200 |

FDNY MEMBERS ONLY

| | |
|-------------------------|--------------|
| FDNY WTC Health Program | 718-999-1858 |
|-------------------------|--------------|

WTC SURVIVORS (AREA WORKERS, RESIDENTS, STUDENTS AND PASSERSBY)

| | |
|------------------------------------|--------------|
| NYC Health & Hospitals Corporation | 877-982-0107 |
| WTC Environmental Health Center | |
| • Bellevue Hospital Center | |
| • Gouverneur Health Services | |
| • Elmhurst Hospital Center | |

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