TESTIMONY BEFORE THE COUNCIL CIVIL SERVICE AND HEALTH COMMITTEES JOINT HEARING ON SURVIVORS STATE OF HEALTH - HEALTH OF 9/11 RESPONDERS AND THE SURROUNDING COMMUNITY MONDAY, DECEMBER 17, 2018

Good morning. Thank you Chair Miller, Chair Levine, and members of the Council here today for holding this important hearing to discuss the health of 9/11 Responders and the Surrounding Community. My name is Steven Banks, General Counsel of the New York City Office of Labor Relations.

The primary purpose of my testimony will to be to describe recent progress the City has made with its municipal unions regarding sick leave benefits for civilian employees who responded on and after 9/11. But before I get into the substance of those recently negotiated benefits, and on behalf of Commissioner Linn, I would like to take this opportunity to note the profound gratitude and respect that the Office of Labor Relations has for all City employees but particularly those who responded to the catastrophic attacks of September 11. It's sometimes taken for granted that our municipal employees answer the call to rescue their fellow citizens and perform all of the necessary functions to keep the City moving and thriving. During and after the 9/11 attacks, all types of City employees did so with honor, pride and courage.

Less than two months ago, in late October, we were able to reach a settlement with DC37 to provide a new 9/11 sick leave benefit and thereby resolve an issue that had been concerning for many of those who responded and helped the City get back on its feet after 9/11 as I just described.

The issue had been that while the City's uniformed services of Police, Fire, Correction, and Sanitation receive unlimited sick leave, civilian employees accrue a set number of days--usually one per month, or 12 per year. Most civilian employees also accrue up to 27 annual leave days which are used for vacation and other personal business. It was brought to our attention that there were and are civilian employees who participated in the rescue, recovery, and cleanup operations related to 9/11 and later developed illnesses which did not require retirement but affected their ability to continue working. The reason I mention retirement is that there have been amendments to the pension law which affect these same employees; in 2005, the landmark WTC Presumption Law was passed, and expanded through amendments thereafter. This groundbreaking law provides a presumption in the New York State Retirement and Social Security Law that certain enumerated illnesses were contracted as the result of participation in World Trade Center rescue, recovery and cleanup operations. Those deemed to have participated according to eligibility criteria in the law may qualify for accident disability benefits and, in the event of death, their survivors may qualify for an accidental death benefit.

The issue of a separate sick leave benefit for 9/11 responders, as a supplement to the sick leave, annual leave, and pension benefits I've mentioned, first came to my attention last spring based on a bill that was proposed in Albany to provide a new benefit. We thought that the appropriate forum to address the issues of the workers was at the collective bargaining table. Paid leave benefits are generally considered a mandatory subject of collective bargaining and provisions regarding various types of paid leave are in all of our collective bargaining agreements. In general, we at OLR do firmly believe that collective bargaining negotiation is the best way to resolve these sorts

of issues, because it allows for all sides to be heard and for all interests to be balanced. From a labor relations standpoint, we in New York City want to be the answer to Wisconsin by demonstrating that collective bargaining works--for the employees and for the taxpayers. We believe we've demonstrated this in a number of ways, including with other paid leave issues. Earlier this year Commissioner Linn testified next door regarding paid parental leave for teachers at the DOE, and a couple of months later we announced an agreement with the UFT providing a new paid parental leave benefit.

In this case, the City, led by Sherif Soliman, engaged with District Council 37 and worked out a mutually beneficial agreement. The key terms are:

- Unlimited sick leave for a civilian employee who participated in WTC rescue, recovery
 and cleanup operations and has contracted a qualifying world trade center condition which
 renders them unable to work. Both of these terms--"rescue, recovery, and cleanup" and
 "qualifying WTC condition" are terms of art which have until now been used for the
 eligibility for pension benefits I described earlier.
- Employees receiving this benefit will be subject to medical monitoring, not unlike our uniformed employees who report to the medical division at their respective agency while out on sick leave.
- For employees who are currently active, and have therefore not benefitted from the pension amendment described earlier, sick leave will be restored retroactively for absences in the past that were connected to the qualifying WTC condition.

Since the agreement was reached with District Council 37 in October, we have approached every other civilian union and offered that they sign on to the same terms. This is necessary because each employee organization has a legal right to negotiate benefits for the employees they represent. To date, nine other unions have signed on, and we expect others to follow suit in the coming weeks and months. We are also working on implementation issues and have a meeting with DC37 tomorrow to discuss the rollout.

We are extremely proud to have partnered with our unions to solve an important issue for those who served us in the face of unspeakable tragedy. I would like to recognize the leadership of the Mayor and the First Deputy Mayor in allowing us to move forward in this fashion. I'll be happy to answer any questions about labor negotiations and the new 9/11 sick leave benefit.



Testimony of the United Federation of Teachers Before the New York City Council Committee on Civil Service and Labor jointly with Committee on Health Regarding Oversight of the Survivors State of Health of 9/11 Responders and the Surrounding Community On Monday, December 17, 2018

Good morning, Chairs Miller and Levine and to the members of the Committee on Civil Service and Labor and the Committee on Health. My name is Ellie Engler, and I am the executive assistant to the president and the director of staff for the United Federation of Teachers (UFT). On behalf of our union's 185,000 members, I want to thank you for this opportunity to offer testimony on the state of the health of those 9/11, survivors who worked, attended schools and lived in the surrounding community.

First, we would like to thank the New York City Council for its advocacy on behalf of our public schools, our members and the children who deserve a high-quality education in a safe and secure environment. Your oversight is crucial and helps ensure that our children and their families receive the services and supports they need to succeed and thrive.

As important, we acknowledge the New York City Council for standing up for all survivors of 9/11, especially the first responders, workers involved in the recovery and clean up, and the students, families and individuals living in the neighborhoods surrounding Ground Zero.

The UFT prioritizes safety and health

The UFT has a long track record prioritizing safe and healthy environments in the schools where our members serve, and our city's children learn. In fact, the union, as an early proponent of these measures more than 20 years ago, brought industrial hygiene and occupational health and safety expertise and services into its portfolio — they hired me. My initial role involved developing and implementing schoolwide safety and health

programs, with an emphasis on the laboratory and vocational shops inspection and remediation protocols for school renovations.

This expertise took on a whole new meaning in the aftermath of the 9/11 attacks on our city. Ten New York City district public schools resided in the World Trade Center zone and many of these neighborhoods, historically known for commercial properties, increasingly housed families.

The neighborhoods in the zone include: Chinatown, Battery Park City, the Financial District and parts of Tribeca.

Protecting our children in harm's way

For any who were in Lower Manhattan that day, it is an experience seared in each of our memories. When the Towers fell that September morning, the first reaction for the thousands of UFT-covered employees working below Canal Street was to insure that their students, patients and people in their care were safe.

Teachers led children through dust plumes and sheltered them under cars and in subway stations as they sought to guide them to safety. Paraprofessionals put their special needs charges on their backs and carried them down stairwells and out into the streets to escape the falling debris. Teachers shepherded students down to the tip of Manhattan and put them on boats to escape the area. Others shielded their students' eyes so young children wouldn't see what we later knew were bodies falling out windows of the Towers. Some spent the night in schools keeping children calm.

No child was injured. All made it out safely.

What happened next was, in some ways, even more difficult. Recovery and cleanup efforts covering what was a major financial, government and educational hub was no small undertaking. We relocated staff and students and supported them through the immediate trauma.

Our journey in the aftermath

Several days after 9/11, together with a team of Department of Education (DOE) industrial hygienists, two members of my team and I inspected seven schools — the buildings most directly in the path of the fallout — in the World Trade Center zone. We observed and monitored city, state and federal cleanup efforts.

Reopening schools in the zone didn't happen overnight. There were rolling openings as each school became ready through February 2002; Stuyvesant High School was the first to open on October 9, 2001. Our union members are professional educators, clinicians, therapists and caretakers of every stripe. We take care of children and we take care of

each other. We provided ongoing mental health counseling support for staff and remained in close contact.

Our team and the DOE occupational physician developed reporting protocols, continued meeting with building staff and with the other hygienists, and monitored the ongoing cleanup through June 2002.

The staggering impact on lives and health

The sheer numbers of those who were directly affected by what happened on that day and who continued living and working in the area is staggering. According to the Victim Compensation Fund, the total exposed population is 425,000, which includes the 90,000 first responders and those working in the private and public trades; the net of which is a universe of approximately 335,000 survivors. Many of these people did not begin to experience illness and develop varying forms of cancer until years later. Across the country the cancer statistics are mounting, including 8,000 responders and 9,000 survivors.

The Victim Compensation Fund has received 35,477 eligibility claims and has made more than 22,800 determinations for injured and ill responders, and/or survivors, or their families totaling \$3.9 billion of the \$7.3 billion allotted by Congress. Unless it is extended, the current deadline for awarding these funds currently is December 18, 2020. But, only 88,000 are enrolled in the World Trade Center Health Program. Clearly, there is tremendous unmet need and the numbers could rise exponentially over time. The UFT supports extending the federal deadline for these funds.

UFT advocacy for at-risk members

It took years before any of us made a connection and understood the breadth of the health crisis that would befall many. Only as first responders started getting sick, with unusual cancers and multiple respiratory problems, did the real impact become public. The message had still not hit home.

In August 2016, I was honored with a first responder award in the name of the late NYPD officer, James Zadroga, by the AFL-CIO. First responder — I never thought of myself, or any of the members of our team as first responders. We were part of cleanup efforts and along with thousands of teachers, city workers, students and residents, walked to and from school breathing air that federal officials only years later acknowledged was not safe. As the years passed, the UFT began hearing from staff who worked in lower Manhattan schools who were now getting sick; suffering from respiratory disease and unusual cancers. Critically, and unexpectedly, students — young men and women in their early 20s — began receiving cancer diagnoses typically affecting people twice their age.

Three of us in the UFT Health and Safety department were on the ground in the aftermath and two of us have been diagnosed with cancer.

In 2017 we began an awareness campaign to let our active and retired members, who we believed to be at risk for these 9/11-related illnesses, know their rights and enroll in the WTC Health Program. We successfully tracked down and contacted more than 1,000 members who taught in the schools near Ground Zero between Sept. 12, 2001, and May 30, 2002, offering assistance to navigate the complex legal and health landscape for compensation. I am enrolled in the program.

This is not easy work. These are people who didn't necessarily see themselves as getting sick from 9/11. These were not people who worked "on the pile." Some of these members have difficulty facing these tough issues about their health. Often they're already sick.

In our most recent forum, on November 29, we reached out to more than 800 members. One of the stories is just unforgettable. An active member who has worked and lived in Chinatown reported her own current cancer, but her husband and cousin had previously died of cancer. She hadn't really come to the forum truly making that connection; she came to the forum just to see what it was about. To date, we've held five seminars. We've touched every member who worked in one of those schools at least three times through our outreach mailing.

Maria Sanabria, was a paraprofessional at Leadership and Public Service High School on Trinity Place, fled the building with students through smoke, ash and debris after the attack. Two of her former colleagues have died of cancer. And after years of breathing and throat problems, she was diagnosed with thyroid cancer in 2017, had surgery and remains in treatment.

But hundreds of our members who were downtown that day still work in the school system, and we've made a special effort to contact them. What became painfully obvious was that the student outreach wasn't happening.

Former students deserve 9/11 services

So many children attended the schools in the zone and were in those buildings in 2001 and 2002. Some of the schools closed. Most have not closed. These former students, now young adults, deserve to know about their eligibility for 9/11 health services and possible compensation for their care. We are not aware of any systematic effort by the DOE to notify former students of the potential health risks. In particular, in our work in Chinatown working with the Chinese Planning Council, it became obvious that the student outreach just wasn't happening.

Shoshana Dornhelm was a student at Stuyvesant High School on September 11, 2001, and for the months and three years that followed. In 2016, she was diagnosed with

Hodgkin's Lymphoma, and had to undergo six rounds of chemotherapy. She is healthy and surviving now. She didn't at first make a connection between her illness and 9/11 until several people in her circle (family friends, former classmates) encouraged her to apply to the WTC Health Fund and seek out other sources that could be available. She has become a vocal spokesperson for students and community members to know their health rights.

While former students were minor children in the direct aftermath of the of 9/11 who required parental permission for medical follow-up, that's no longer the case. Our work with our members shows we can reach survivors. This undone work needs to happen and happen soon.

What the City Council can do

Chairs Miller and Levine, we seek your partnership in bringing awareness to the former students about the World Trade Center health programs and the Victim Compensation Fund, as the clock is ticking. You could use your oversight authority to request that the DOE do whatever is at its disposal to contact these former students.

The department is in the best position to know how monumental its task is. At minimum, it could send hard mail and electronic mail blasts. It should use a variety of media, from local print and broadcast to social media platforms. If older records require an electronic transfer, there are several certified entities capable of doing this sensitive work; in at least one instance, the department already has secured funding to do it. We would gladly work with the DOE to connect it to these resources.

We thank you for your consideration. Think of the powerful difference we can make in so many lives, moving this, the next step, forward.

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Jennifer Aguiluz John Chiarovano Carl Gandolfo Sammy Gounden Lauren Hartnett Deaths from 9/11 caused diseases currently greatly outnumber those lost on that fateful day. We lost 2 members, Carlos Lilo and Ricardo Quinn, to the terrorist attack. In the course of the last 17 years, 100 additional members have made the supreme sacrifice in service to our great city.

Our active duty work force on 911 was 2500, 431 are currently still on active duty and are being treated for 90 separate health conditions related to work at the WTC, that equates to 17 % of the work force.

Of those 431, 88 or 22% are currently battling cancer. It bears mentioning that the average age of these members is 49. They are now suffering from diseases that are usually seen in septuagenarians.

Asbestos-related cancers, notably lung cancer, can take 20 years for symptoms to show. These cancers are beginning to appear at an alarming rate. Bearing witness to that fact in this month alone I have attended the funerals of 3 of my members. That leaves mothers & fathers burying children and spouse burying their loved ones. The wail of bagpipes and stately departmental funerals is but little consolation.

We also have 700 retirees under treatment. These retirees while a bit older are developing acute health issues at an alarming rate. So of the 2500 EMS members employed on that fateful day, 1009 are being treated for health related issues caused by the terror attack.

We have rebuilt The World Trade Center, we have pledged that we will never forget their sacrifice. Yet problems still remain in the adjudication and administration of 9/11-related claims. The Governor has legislated world center related diseases to be presumptively related to the rescue and recovery efforts. But because the link between a particular medical condition and WTC exposure is not always definitive, the city has challenged a high proportion of 9/11-related workers' compensation claims.

The denial rate for NYCERS 911 disability pensions remains unchanged at around 50%.

While much has been learned, the entire spectrum and trajectory of WTC-related disorders and their mechanisms of onset and persistence remain to be fully described and while those mechanisms are continually evolving we need to maintain, extended and grant options to our members.



NYC Council Committees on Health and Civil Service and Labor Hearing-Dec. 17, 2018

Good morning, and thank you for this opportunity to appear here today. My name is Karen Mazza, and I am the Deputy Executive Director at NYCERS. With me today is Ilyse Sisolak, NYCERS General Counsel. Our Executive Director, Melanie Whinnery sends her regards and regrets that she could not be here today as she is traveling back from a previously planned visit with her mother.

For background, as you may know, NYCERS is one of the City's 5 defined benefit plans. It is the largest municipal pension fund in the country and provides benefits to a diverse population of city employees from sanitation workers and correction officers to city council members and the Mayor.

NYCERS provides disability benefits to its members under several provisions of law, but in light of today's agenda, I will focus on the laws related to the World Trade Center – also referred to as WTC

The World Trade Center Disability Law provides, in part, that certain disabling injuries, illnesses or diseases incurred by certain State and City employees, including NYCERS' members, who "participated in World Trade Center rescue, recovery or cleanup operations" are presumed to have been incurred as the result of an accident sustained in the performance and discharge of duty. For any member to qualify for a disability retirement under the WTC Law, the member must file a Notice of Participation and be verified as having participated in WTC rescue, recovery and clean-up operations that meet certain criteria.

The member's Notice of Participation is filed with NYCERS and then provided to the agency where the member worked during the qualifying period. The agency is asked to either verify the member's participation or state why the agency could not verify that the member participated. If an agency cannot verify participation, the member is given an opportunity to dispute the agency's findings by submitting additional evidence to support the claim. If the agency still cannot verify after reviewing the additional evidence, the member's case is reviewed by NYCERS Board of Trustee WTC Review Committee. A verified Notice of Participation is a placeholder in the event the member subsequently becomes ill.

If a member becomes ill and applies for a WTC Disability Retirement, they submit medical evidence in support of their application, and the case is brought before the NYCERS Medical Board. The Medical Board is an independent board of three physicians appointed pursuant to the NYC Administrative Code. The Medical Board must determine whether the member is

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suffering from a WTC qualifying condition or impairment, as defined by law. To make this determination the Medical Board reviews all of the medical evidence, and conducts an interview and physical examination of the member. By law, the Medical Board's determination regarding disability is binding on the Board of Trustees.

If the Medical Board determines that the member is disabled by a WTC qualifying condition, then the Medical Board is required to presume that the condition is the result of the member's participation in rescue recovery and clean up. However, this presumption can be rebutted if the Medical Board finds that the documentation, interview and examination support a finding that the presumption is rebutted. In that case, the Medical Board makes a recommendation to the Board of Trustees that the WTC presumption is rebutted. The member may appeal the Medical Board's recommendation to the NYCERS Board of Trustees. After such an appeal, the Board of Trustees makes a final determination regarding whether the member qualifies for a disability retirement under the WTC Law.

That's the World Trade Center disability process at a very high level. There are many more detailed steps in the process, and every member's circumstances is different.

I encourage you to visit the World Trade Center section of our website. It contains information helpful to members, such as information on the law, forms, frequently asked questions and links to other organizations, such as the World Trade Center Health Program, the 9/11 Victim's Compensation Fund, Workers' Compensation and more. There are also two reports from our Executive Director that highlights the improvements that NYCERS and our Board of Trustees have made in the WTC and disability process.

The entire NYCERS team is committed to working with our stakeholders, the Medical Board, and the Board of Trustees to continue to make changes that would help our members who served NYC during a terrible tragedy to receive all benefits that they are entitled to expeditiously and compassionately.

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December 17, 2018

Thank you committee chair Daneek Miller and Council Members for holding this hearing. I'm here to speak for the broader 9/11 Community who were employed by the City of New York.

- My name is Michael Barasch, managing partner of the law firm Barasch & McGarry. I am joined by my associate Ret. FDNY Deputy Chief Richard Alles, who was the former political and legislative director of the UFOA. I need not mention that he was also a 9/11 first responder.
- Our firm represents over 12,000 people in the 9/11 community. Nearly every day we file a new wrongful death claim with the Victim Compensation Fund. It is truly horrifying.
- Our client NYPD Det. James Zadroga's autopsy revealed ground glass in his lung tissue. Think about that. Also found asbestos, chromium, lead, benzene and a host of other known carcinogens.
- Everyone, uniformed an non-uniformed, were breathing the same toxic dust as Jimmy Zadroga.
- According to NIOSH and the CDC, nearly 20,000 people so far have had their cancers linked to the WTC toxins, including:

- 9,000 first responders nationwide, 1700 FDNY members, and 8,000 civilians
- 190 Firefighters and Fire Officers have had their <u>deaths</u> linked to the toxins so far.
- And thousands of other non-FFs have died as well.
- EPA infamously assured America that the "air is safe".
- Once Congress realized that the EPA had misled 450,000 people in the 9/11 community, it did the right thing in 2010 and 2015 by passing and extending the Zadroga Health & Comp Act.
- But 2 problems: 1) 2 years from tomorrow the VCF will expire for good. People aren't going to stop getting sick and dying and; 2) there isn't enough money set aside to provide compensation for them.
- In fact, the rates of cancers, respiratory illnesses and deaths are so much higher than anyone envisioned in 2015 that on February 1st, the VCF Special Master will soon be announcing cuts in future awards!
- Congress needs to act again and extend the VCF this time with enough money to take care of *everyone* who was exposed to the deadly toxins.
- Every City employee, not to mention thousands of residents and office workers, were breathing the same toxic dust as Jimmy Zadroga. Nearly 90,000 union members were involved in the rescue, recovery and cleanup operations. They include members of the FDNY, NYPD, EMS, the building trades, Sanitation, Correction, various titles in the UFT and DC-37, and thousands of City employees who worked in the court system, Dept. of health, Building Dept., DCAS, and our schools, to name a few. The toxins did not discriminate based on whether someone was wearing a uniform.

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• NYCERS is affecting responders' VCF awards. By delaying disability pension claims and reclassification applications, it is delaying their VCF lost earning claims --- all for what?! For many, they already have been granted disability pensions for their non-WTC illnesses or non-physical WTC illnesses, like PTSD. They aren't asking for any more money from the City, just an acknowledgment that they are sick and disabled due to the WTC toxins. It's truly shameful. Please: Do the right thing and expedite these claims.

December 17, 2018

Testimony to the Council of New York City on behalf of the 9/11 Survivors, Responders, Victims, and their families

Mary Fetchet, Founding Director of Voices of September 11th Stephanie Landau, Program Director Voices of September 11th

My name is Mary Fetchet, and I am founding director of Voices of September 11th, an organization I co-founded in 2001 following the death our 24-year-old son, Brad Fetchet who was working on the 89th floor of the South Tower. I am here today with Stephanie Landau, who has been VOICES Program Director for the past 12 years.

At the time of the attacks I was a clinical social worker, and established VOICES to provide support services, and access to resources and mental health care for all those who were impacted by the attacks on 9/11. Over the past 17 years, our staff has provided over 160,000 hours of support services and a wide range of programs for victims' families, survivors and responders, and their families. For 6 years, VOICES worked along with other outreach partners to assist survivors and responders in accessing treatment through the World Trade Center Program. Today, we continue to be focused on providing continuity of care by working collaboratively to provide programs that address the long-term mental health needs of the 9/11 community.

Our testimony is focused on the long-term needs of 9/11 survivors, responders, victims, and their families.

Victims' Families

Since 2001 the needs of victims' families have evolved. In 2015 VOICES conducted a scientific research study to evaluate the long-term needs of 600 victims' families. The findings demonstrated that 15 years later many families had a range of needs.

- 1/3 of family members are resilient and have been able to integrate and accept the loss of their loved one, and move forward in a productive way.
- 1/3 had mental health needs that fluctuate from time to time possibly based on subsequent losses, news of other tragedies, or changes in their support system
- 1/3 are still experiencing serious mental health conditions such as depression, anxiety, and PTSD
- Many families who we contacted were unwilling to participate in the study for a variety of reasons. Most indicated that reflecting back on their personal experience would be too painful, would reopen "old wounds" or complicate their mental health conditions.

Based on our research and our daily contact with 9/11 families, we have found longstanding mental health issues that have not been addressed for children of the victims' who are now young adults, including misdiagnosis, intergenerational issues, substance abuse, and other developmental challenges.

For example, a victims' child who was 13 yrs. old at the time, struggled through high school and college, and was misdiagnosed and treated with stimulants for attention deficit disorder, when in reality he had anxiety and depression. This in turn led to substance abuse and the need for years of private therapy.

Another example of a mental health stressor is the continued identification of human remains. The Office for the Chief Medical Examiner's office still has over 7,000 unidentified human remains. Of the 2,753 victims at the World Trade Center site, over 1,100 victims have still not been identified. Many families by choice have been notified multiple times.

Over 17 years later, we receive calls from victims' families regularly that are contacting us for the first time asking for support services. Many have never sought mental health treatment and their conditions have been magnified due to other losses, lack of support and unforeseeable circumstances that are out of their control.

<u>Survivors</u>

In 2006 VOICES worked with Morgan Stanley to analyze the number of survivors who were present in Lower Manhattan on 9/11. We estimate that over 400,000 people lived, worked or went to school within a quarter of a mile of the WTC on 9/11. Of that number, only about 18,000 survivors are enrolled in the WTC Health Program, and many do not know they qualify or that it's still open. Some survivors still reside in the area, yet others have retired or relocated to other parts of the country.

Some survivors have become sick and sought treatment for illnesses with their medical doctors, not recognizing the connection with their exposures to the WTC site. As an example, we received a call from the husband of a woman who worked at a school in the area and was diagnosed with brain cancer. Her husband called the day before her surgery wondering if she should apply to the program. We helped expedite her application.

Some terminally ill survivors never recognize the connection to their 9/11-related exposures and it's not until many years after their death that their family contacts us asking for help. Although they've perished we can assist the families by connecting them with the attorneys who will help them apply to the Victim's Compensation Fund.

The overlooked "survivor community" are the thousands of individuals who worked in the WTC buildings but weren't at work that day. Many of them lost hundreds of friends and colleagues that day and were tasked with rebuilding their companies.

Responders

Nearly 75,000 responders are currently registered in the WTC Health Program. John Feal has been working tirelessly in helping responders apply to the program. We are often contacted by individuals who have either moved out of the area, or from responders who came from other parts of the country to work in the rescue and recovery effort. For instance, we were contacted by a response team from Phoenix, Arizona who had 42 colleagues who came to the area.

As of September 30, 2018 over 45,000 survivors and responders are in treatment for mental health conditions and sometimes life-threatening illnesses. (From the total group 14,432 hold at least one mental health diagnosis, not including the 282 deceased members with mental health diagnoses). Of that number, 2,104 have died (1,902 responders, 202 survivors). Since September at least 35 known responders have died.

Families

Across the 9/11 community the families of victims, survivors and responders are often overlooked and don't qualify for support services or mental health care.

While survivors and responders are sick and receiving treatment, their spouse and children have additional responsibilities of caring for an individual with life threatening illness and mental health conditions who needs assistance with activities of daily living and frequent doctor's appointments. In most instances the sick individual is the breadwinner and is unable to work, causing financial stressors in meeting their monthly expenses. Spouses who work have to take unpaid time off work to care for their family members. The illness also impacts the parent's ability to provide emotional and physical support of their children such as attending their daily activities. and providing and physical limitations.

For the families of the deceased, there are funerals and paperwork to plan and complete, in addition to paying the funeral expenses.

Overall Challenges

There continues to be challenges for Responders, Survivors and their families in accessing information from the layers of agencies and organizations tasked with specific services including those from the city, state and federal governments, as well as interfaith organizations, unions, and corporate HR and Employee Assistance Programs. Many of the groups have similar names which adds to the confusion, at a time when a person is also overwhelmed with diagnoses, finances, and medical appointments.

In addition to the myriad of services, there are also many different deadlines that have changed over the 17 years since 9/11 and are easy to lose track of. For example, the federally funded VCF, NY State Workers Compensation Board, and City Pensions all have different filing deadlines to ensure financial benefits. This creates a great deal of added stress on the individual

and their family/caretakers, usually taking multiple calls to different places to ascertain they qualify for a program and then to fill out the paperwork.

Furthermore, though they occur in abundance within the population, mental health conditions are not compensated financially through the federal programs, for either the victim's family, responder, survivor or their families. However, mental health is just as important as a person's physical well-being, and those with mental health challenges often suffer silently due to stigma.

The families we speak to regularly are looking for ways to navigate these systems and get through the paperwork easily all the while worrying about a family member who may be dying. The family members themselves may be physically sick, though not covered. An example would be the wife who washed her responder husband's clothes and was exposed to the same toxins he was when shaking out the clothes each night. They are all suffering with little acknowledgment and limited supports.

Science tells us that the needs and demands are only going to get worse. More and more will come forward as they age and become sicker. Almost daily there is an article in the paper, a television profile etc. of another WTC related death. This too adds additional stress on the families.

There was an estimated 800 -1000 tons of asbestos that was a part of the infamous dust cloud on 9/11. Asbestos-related illnesses have a lengthy latency period. According to a WTC Registry study over 400,000 were exposed to asbestos in addition to the other toxins. As we approach the 20th anniversary, we expect an increased number of those with asbestos related illnesses to come forward, and many of whom will die due to this exposure, leaving behind families who need support. We also realize that with the 20th anniversary coming, there will be more news coverage, more illness, more stories, and wounds that will be opened through it all, leaving thousands of people still with limited support.

We are here today to support our 9/11 community to ensure they receive the long-term support services and mental health care they need and deserve. In addition, we support John Feal and the FealGood Foundation, who has been a longtime friend and partner and the Attorneys who represent the Survivors and Responders and their families with great empathy as they continue to battle for additional funding for the Victims' Compensation Fund, and for fair treatment and sick leave for all those impacted.

We look forward to the opportunity to discuss this further and to answer any questions you may have as we move forward.

Contact information:

Voices of September 11th – 203-966-3911

Mary Fetchet, mafetchet@voicesofsept11.org

Stephanie Landau, slandau@voicesofsept11.org



VOICES Resiliency Symposium

Knowledge to Practice: Pathways to Long-Term Healing

A Victim-Centered Approach

Sunday, September 9, 2018

Marriott Downtown Hotel | 85 West Street | New York City Registration Opens: 8:00 am | Program: 9:00 am - 4:00 pm

The Multigenerational Impact of Trauma on Survivors and Responders

Yael Danieli, PhD

Director, Group Project for Holocaust Survivor and their Children Founder, International Center for the Study, Prevention & Treatment of Multigenerational Legacies of Trauma

Research to Practice: Treatment of PTSD and Anxiety

Rebecca Rosen, PhD, Mental Health Director, World Trade Center Clinical Center of Excellence, Bellevue Benjamin Suarez-Jimenez, PhD, Postdoctoral Research Fellow, Department of Psychiatry and New York State Psychiatric Institute, Columbia University Medical Center Joann Difede, PhD, Director of the Program for Anxiety and Traumatic Stress Studies, Weill Cornell Medicine

Supporting Victims of Mass Tragedy: National and International Perspectives

Sue O'Sullivan, Chair, International Network Supporting Victims of Terrorism and Mass Violence
Kathryn Turman, Assistant Director, FBI Victim Services Division
David Schonfeld, MD, Director, National Center for School Crisis and Bereavement,
USC Suzanne Dworak-Peck School of Social Work

Giving Voice to Victim's Families and Survivors

Fred Guttenberg, Founder of Orange Ribbons For Jaime, Father of Jaime Guttenberg, and Brother of Michael Guttenberg, MD, FDNY EMS Fellow, who died of 9/11 related illness JoAnn Bacon, Co-Founder & Director, Charlotte Helen Bacon Foundation, Mother of Charlotte Bacon Mary Fetchet, LCSW, Founding Director, Voices of September 11, Mother of Brad Fetchet

Vicarious and Shared Trauma: Promoting Resilient Responders

Carol Tosone, PhD, Professor and Director of the DSW Program in Clinical Social Work at New York University Silver School of Social Work

Cultivating a Resilient Community: A Pathway to Thrive

Mollie Marti, PhD, JD, President, National Resilience Institute

Register online at www.voicesofseptember11.org, or phone (203) 966-3911



Appearance Card
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Date:
(PLEASE PRINT)
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Name: Boash Magaren lawfirm
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Name: Mark Tare
Address: NYC DOHWH, WTC Health Registry
I represent:
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