

FINAL PROGRESS REPORT

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September 1, 2012 to February 28, 2015

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ABSTRACT

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9/11 Environmental Action (9/11EA) carried out an effective outreach and education project aimed at increasing awareness of the World Trade Center Health Program (WTCHP) for affected survivors (residents, students and area workers), locally and nationally, WTC disaster relief volunteers and New York City Department of Sanitation responders. Our partner StuyHealth, an organization of affected Stuyvesant High School alumni, focused outreach efforts on affected young adults, locally and nationally.

Some 400,000 survivors were exposed to the WTC disaster. The majority are likely not aware of the WTCHP, or think it is for responders only. Survivors remain hard-to-reach for many reasons including the widely disseminated official pronouncements that WTC dust and smoke posed no health threat, and the absence of a specialized treatment program for survivors until 2007. Those who became sick from their exposures sought care from private physicians, who lacked the needed expertise. Many survivors and providers are not aware that certain health problems have established links to 9/11.

Tens of thousands of volunteers joined in the 9/11 disaster relief effort. Some currently reside in the greater New York metropolitan area, others in their home states. Volunteers share some of the same barriers to care as survivors, including the 'disconnect' between exposures and symptoms. They tend to see themselves as underserving of care, as helpers to the sicker population of responders. Hosting disaster relief organizations often have not informed volunteers of their eligibility for WTCHP care. Instead, our Volunteers Outreach Coordinator had to transcribe numerous paper contact sheets she possessed from her work as a Salvation Army supervisor after 9/11.

Many DSNY responders are not aware of their eligibility for treatment or for the monitoring program.

9/11EA devised effective strategies to address barriers for both survivors and volunteers, using both traditional and social media outreach methods. To address the fact that many survivors are being treated for WTC conditions by private physicians, our messaging emphasized the added value of care at a specialized center by doctors who are expert. We attended dozens of community meetings and forums, distributed thousands of brochures and postcards.

9/11 Environmental Action (1E11-OH010451-01) ABSTRACT cont'd

We created a new 9/11EA website as well as educational materials to promote the WTCHP and counter the widespread confusion about WTC programs. We pushed messages on Twitter, Facebook and YouTube, and worked with agencies and others to push WTCHP information out in mailings and emailings. We created an instructional video for survivors on how to enroll in the WTCHP and provided assistance to guide survivors or responders through the enrollment process. The combined reach of our direct and indirect outreach, to survivors, volunteers and DSNY responders, was 898,292.

StuyHealth increased awareness the about the WTCHP and the National Provider Network, among young adults, including many now residing beyond NYC, using Facebook, Twitter, email lists, a new website and a video PSA. StuyHealth grew its membership to 463 and its reach exceeded 5000 young adults

9/11EA's project led to increased awareness of and enrollment in the WTCHP by survivors and responders. This will result in improved health outcomes for those receiving WTCHP monitoring and treatment. There is an ongoing need for outreach.

SECTION 1

Significant Findings:

1. More than 400,000 survivors were exposed to the WTC disaster. Most of them are likely not aware of WTCHP. We found that survivors remain hard-to-reach for a host of reasons including: the early widely disseminated official claims that WTC dust and smoke posed no health threat, the near absence of WTC research on survivors, the absence of a specialized treatment program for survivors until 2007. Those who became sick from their exposures sought care from private physicians, who lacked the needed expertise. Many survivors are not aware that certain health problems have established links to 9/11. Moreover, psychological barriers persist, including avoidance of the idea that one's health problems are linked to 9/11. Survivors who may know about 9/11-related health benefits are confused about the fact that there are 3 WTC health-related programs that require separate application, or believe that treatment is available for responders only. Finally, some of those whose health was affected are now dispersed, throughout or beyond New York City. Successful outreach strategies must address these barriers. The need for outreach is ongoing.
2. Tens of thousands of volunteers poured into Lower Manhattan to join in the 9/11 disaster relief effort. Some currently reside in the greater New York metropolitan area, others have long since returned to their home states. Volunteers share some of the same barriers to care as survivors, including the 'disconnect' between exposures and symptoms. Too, they tend to see themselves as underserving of care, as helpers to the sicker population of responders who toiled on 'the pile'. Finally, many have moved on to relief work at other disasters. There has not been a consistent effort on the parts of the hosting disaster relief organizations to inform volunteers of their eligibility for WTCHP care. The need for outreach is ongoing.
3. Enrollment data show that WTCHP is underutilized by responders who worked for the NYC Department of Sanitation (DSNY). Many DSNY affiliated responders are not aware of their eligibility for WTCHP treatment, especially for the monitoring program. The Department has not made efforts to inform workers comparable to those made by the FDNY, for instance. The need for outreach is ongoing.
4. Many of those who lived or attended school in the NYC disaster area on and after 9/11 are now young adults, many of whom dispersed to schools and colleges in other neighborhoods and other parts of the country. This social media and tech savvy population needs outreach for both the NYC Survivor Program and the Nationwide Provider Network. Psychological barriers, including avoidance of 9/11-related content, affect young adults, in addition to stigma attached to 9/11-related physical and mental health issues.
5. More than a decade after 9/11, in the current crowded and complex media landscape, all populations would benefit from both "niche" marketing as well as mass marketing for the WTCHP, from both conventional outreach methods as well as social media methods.

Translation of Findings:

9/11EA devised effective strategies to address the findings for both survivors and WTC volunteers, using both traditional and newer social media outreach and education methods. To address the fact that many survivors are being treated for WTC conditions by their private physicians, we employed messaging that emphasizes the added value of care at a WTC Center of Excellence by doctors who are compassionate and expert. For survivors and volunteers, we emphasized the new coverage for certain cancers, and the WTCHP's network of cancer treatment centers. We used the October 3, 2013 registration deadline for the September 11th VCF as a way to get the attention of both populations and to motivate them to enroll in WTCHP. We created a user-friendly website and

materials that promote the WTCHP, counter the widespread confusion among WTC programs, and were designed not to trigger avoidance. We created an instructional video for survivors on how to enroll in the WTCHP and also provided individual enrollment assistance to guide survivors and responders through the process. We emphasized to both survivors and volunteers that their enrollment would contribute to more effective WTC disease surveillance for their entire cohorts. Our WTC Volunteers Outreach Coordinator transcribed many paper contact sheets she possessed from her 9/11-related work as a Salvation Army supervisor in order to send out emails with WTCHP information. The combined reach of our direct and indirect outreach, to survivors, volunteers and DSNY responders, was 898,292.

StuyHealth (SH) increased awareness the about the WTCHP and especially the National Provider Network (NPN) among its young adult members living outside the tri-state area, using social media its Facebook page, Twitter and a video PSA. SH launched a professional, informative, comprehensive website, important for a population that prefers to get information online. Its PSA advertising the WTCHP was geared toward a population that will avoid depressing reminders of the attacks. SH grew its membership to 463 and its reach has exceeded 5000 young adults.

Outcomes:

End Outcomes: 9/11EA's project led to increased awareness of and enrollment in the WTCHP by survivors and responders. This will result in improved health outcomes for those receiving monitoring and treatment. SH increased awareness/enrollments among its young adult survivors, resulting in improved health outcomes for enrollees.

Intermediate Outcomes: Feedback to NIOSH/WTCHP from 9/11EA and SH has improved education, communications and delivery of WTCHP services. SH's recommendation for WTCHP to offer an online application has increased the ease of applying. SH's feedback has improved the interface between members and NPN. 9/11EA has provided insights to other grantee groups and NIOSH, for example, our "3 WTC Programs" flier is now being used by 3 grantee groups, 2 CCEs, and NIOSH is awaiting approval of its own version.

Potential Outcomes/Recommendations:

We recommend:

- that NIOSH continue to fund dedicated outreach to survivors and responders by community-based and labor organizations. NIOSH/WTCHP enrollment data have demonstrated the success of these efforts.
- that NIOSH consider mounting mass media campaigns, such as an expanded subway ad campaign for all subway lines for at least 6 months, that would be synergistic with the outreach efforts of outreach groups.
- that NIOSH work effectively to gain the cooperation of the relevant institutions, whether those are city agencies, such as DSNY or NYCHA, or disaster relief organizations, such as the American Red Cross, in ensuring that eligible survivors and responders become aware of the WTCHP care available to them.
- that NIOSH/WTCHP institute a smart phone app process for enrolling in the WTCHP, which will facilitate enrollments by young adults, among others.
- that NIOSH Office of Extramural Programs include in its next research RFP a request for interdisciplinary studies of WTC-related barriers to care with a Community-based Participatory Research approach.
- that the Federal Government learn the lessons from the WTC disaster, and in recognition both of the scope of disaster-related health impacts, and also of the lasting barriers to care stemming from its false safety assurances, approach future disasters in a truthful manner that protects public and occupational health.

SECTION 2

I. 9/11 Environmental Action - Background

For WTC survivors (residents, students and area workers) and for WTC disaster relief volunteers (deemed responders by the James Zadroga 9/11 Health and Compensation Act), a major disparity has emerged between estimates of those likely suffering WTC disaster-related health effects and the number of those utilizing the services of the World Trade Center Health Program (WTC HP).

The WTC disaster exposed hundreds of thousands of people to toxic smoke and dust as well as to traumatizing events. A 2009 WTC Health Registry study of all exposed subpopulations of responders and survivors, estimated that “as many as 88,600 adults have had symptoms of posttraumatic stress disorder and as many as 40,000 adults have developed new asthma as a result of their WTC exposures.” Research continues to show that for many of the WTC-exposed populations, these and other WTC conditions have become chronic.

Researchers with the World Trade Center Environmental Health Center (WTC EHC), which treats affected residents, students and area workers, estimate that more than 58,000 residents and more than 300,000 local workers were living or working below Canal Street, approximately 1 mile from the WTC site on and after 9/11.

Also exposed were more than 35,000 children, a population vulnerable to harm from toxic exposures. All were residing or attending school or daycare in Lower Manhattan on and after 9/11. From a 2003 health survey of its pediatric cohort, the Registry found a post-disaster doubling of the already high rate of asthma among children under age five in the Northeast. Other studies documented a range of mental health problems, manifesting in age-related ways.

To address the scope of disaster-related health problems, the Zadroga Act provides an additional 25,000 treatment slots to the WTC Health Program (WTC HP), for responders and survivors, respectively. The WTC HP’s Survivor Program, however, has remained underutilized. The patient population has ranged from approximately 6,000 to 8,100 patients, including adults and children for the grant period.*

Challenges for outreach to WTC survivors

Many of the challenges faced by grantee groups stem from flaws in the federal and city government response to the WTC disaster. In the weeks and months after 9/11, residents, school parents and local workers were left to struggle on their own to protect themselves and their children from toxic exposures indoors and out. People had no access to accurate environmental health information, appropriate public health guidance, or proper medical evaluation and care. Instead, survivors’ legitimate concerns and calls for help were met only with official reassurances that the air was ‘safe’ and that any health problems they were experiencing were

temporary. Moreover, there was no discussion of the need for proper environmental cleanup; residents and others were instructed to clean the dust and debris themselves.

In our more than a decade of work with Lower Manhattan survivors, we have found that the continuous, heavily publicized government attempts to downplay 9/11-related health risks, including health risks to young children and the developing fetus, helped to ‘disconnect the dots’ between exposures and resulting symptoms. There was no medical validation of the link between health effects and WTC; there was no program set up to conduct health screenings after the disaster, something to which responders had early access. There was no public health guidance made available to New York City doctors until 2008, no WTC pediatric guidance until 2009.

The exclusion of affected neighborhoods North of Canal Street in Manhattan, as well as in western Brooklyn, by both the EPA cleanup program and the City/Federal WTC Health Registry conveyed the message that these areas were not polluted by WTC dust and smoke.

Finally, there was no WTC-specialized program dedicated to treating survivors until 2007, when the WTC Health Impacts Clinic, with an infusion of millions of City dollars became the WTC Environmental Health Center (WTC EHC). There was no WTC pediatric program until 2008.

Many residents who moved away long before the WTCHP was available to survivors are likely not aware of their access to care. Exposed students have dispersed to high schools and colleges outside the NYC disaster area. Significant numbers of office workers are in different jobs, often in other parts of the city.

Further reasons for the underutilization of the WTC EHC have to do with the nature of the disaster. Some survivors feel undeserving of care in the face of the loss of so many lives; it was not uncommon for people suffering health effects in the midst of government denials to fear stigmatization. Some survivors feel that only responders are deserving of care and many survivors think that federal WTC health care is available only for responders. An August 2012 journal article on focus groups conducted by the Registry affirms earlier research findings that disaster-related post-traumatic stress operates as a barrier to care.**

Many survivors would rather believe their health effects have nothing to do with 9/11, even when the nature of their exposures, symptoms and timing of symptom onset point overwhelmingly toward that cause. New enrollment procedures required by Zadroga have made the process of applying more complicated and time-consuming. This is especially true with regard to the gathering required documents going back more than 10 years in the past.

Challenges for outreach to 9/11 disaster relief volunteers

In addition, following 9/11, tens of thousands of volunteers poured into Lower Manhattan to join in the disaster relief effort. Volunteers worked for many weeks or months on the perimeter of the pile or at outdoor stations and area buildings in close proximity. Some currently reside in the greater New York metropolitan area, others have long since returned to their home states. Outreach Directors for the Responder Program agree that this population continues to need outreach and education efforts.

Volunteers share some of the same barriers to care as survivors, including the ‘disconnect’ between exposures and illnesses or symptoms. They too feel undeserving in light of the tremendous tragedy faced by family members of those who perished in the towers. Too, they tend to see themselves as helpers to a much more heavily exposed, and now sicker population of responders who toiled on ‘the pile’.

Challenges to reaching the affected young adult population will be address in the StuyHealth section of this report.

It is critical that symptomatic WTC survivors and exposed WTC disaster relief volunteers be linked to the care provided by the WTCHP.

**Please note: all estimates are drawn from the NYC Health Department’s WTC Health Registry, the Mayor’s WTC Medical Working Group Reports, the Clinical Guidelines for Children and Adolescents Exposed to the WTC Disaster, peer reviewed studies, expert testimony at Congressional hearings and WTC Health Program data.*

***Welch AE, Caramanica K, Debchoudhury I, Pulizzi A, Farfel MR, Stellman SD, et al. A qualitative examination of health and health care utilization after the September 11th terror attacks among World Trade Center Health Registry enrollees. BMC Public Health 2012, 12:721
<http://www.biomedcentral.com/1471-2458/12/721>*

II. Project Summary Description:

The 9/11 Environmental Action project has utilized innovative social networking techniques, as well as traditional outreach methods, to reach as broad a population as possible. The project has disseminated information about who is eligible for WTCHP membership, for which programs (Survivor Program, Responder Program or National Program), and provided guidance, including individual assistance, on how to enroll. The project has mainly focused on survivors, but included a significant component of outreach to and collaboration with disaster relief volunteers. It included collaborations with the survivor organization StuyHealth, to reach a

population of affected adults, locally and nationally; and with the Ground Zero Fellowship to reach a population of affected disaster relief volunteers, locally and nationally. Over time, we added a number of Project Aims, as we worked with other grantee groups and WTCHP and NIOSH personnel.

III. Key Project Aims:

To conduct outreach and education to increase awareness and utilization of the services of the WTC Health Program among affected populations, including WTC Survivors (residents, students, and area workers) locally and nationally; and WTC Responders (disaster relief volunteers), locally and nationally; to provide enrollment assistance and will work to increase retention. Early in the grant period, our efforts expanded to include retention for both survivor and responder programs.

To work in partnership with StuyHealth, to work collaboratively with the Ground Zero Fellowship in outreach to young adults and disaster relief volunteers

To engage in collaboration with outreach staff at the WTCHP Centers of Excellence, the WTC Health Registry and with other NIOSH grantee groups with reach and capacity that complements our own.

Added Aim: In the course of our work, we developed materials and conducted outreach targeted to responders employed by the Department of Sanitation of New York (DSNY).

IV. Methodology

Under the grant, 9/11 Environmental Action conducted a World Trade Center Health Program (WTC HP) outreach and education project to increase awareness and utilization of the services of the WTC Health Program among WTC Survivors, including residents, students, and area workers, both locally and nationally. In addition we worked to increase awareness and utilization WTC HP services among WTC Responders who served as disaster relief volunteers on and after 9/11, locally and nationally. We provided extensive WTC HP enrollment assistance.

For the project, 9/11 EA built upon our strongest assets: our thorough knowledge of WTC-related exposures, health impacts and WTC HP health services, our more than ten year history of collaboration with the full range of 9/11 stakeholder groups, our extensive networks of 9/11 contacts in New York City and beyond, and our deep understanding of barriers to care for the survivor and disaster relief volunteer audiences.

We partnered with the survivor organization, StuyHealth to reach an audience of affected young adults, locally and nationally. Organized on Facebook, StuyHealth has a membership of 400 alumni of Stuyvesant High School, five blocks north of the WTC site.

We hired a WTC disaster relief volunteer who served as a Salvation Army supervisor to work part time as our WTC volunteers outreach coordinator. We partnered with the organization, the Ground Zero Fellowship to reach an audience of affected disaster relief volunteers, locally and nationally.

Our outreach efforts were coordinated with NIOSH, the WTC Health Program's Survivor Program, Responder Program and National Program, as appropriate. We collaborated closely with the WTC Environmental Health Center (EHC) on outreach to local survivors. In addition, where appropriate, we coordinated/collaborated with the Outreach and Education staffs of the Mount Sinai Responder Clinical Center and Data Center, the SUNY Stony Brook Responder Program, New York City Department of Health and Mental Hygiene's WTC Health Registry.

Our traditional methods included: holding community forums and disseminating WTCHP literature and promotional items at community venues such as residential complexes, area libraries, community board offices and community meetings. In addition, we approached schools, college and university administrators, the NYC Department of Education, the Retirees Services Division of the United Federation of Teachers and other institutional entities to provide materials and presentations and, where appropriate, re-mailing of WTCHP informational emails to their lists.

Our innovative social networking methods included using Facebook, Twitter, GoogleAds, YouTube and the 9/11EA and StuyHealth websites to broadly disseminate information on who is eligible for the WTC HP and for which specific programs, and to provide guidance on how to enroll. These tools greatly expanded our reach and helped to increase the accessibility of WTCHP information for prospective survivor or responder enrollees.

We used social media to drive traffic to our websites, as well as to the federal WTCHP website. We created a new website for both 9/11EA and new Facebook pages, for 9/11EA as well as the WTC Disaster Relief Volunteer Facebook page, provided program updates and news information. (StuyHealth created a website, which will be discussed in the StuyHealth section of this report.)

We disseminated the key messages developed by the WTC Environmental Health Center the Responder Program, for survivors and responders, respectively.

We crafted a set of additional outreach materials specifically tailored for each of our target audiences of survivors and disaster relief volunteers, and DSNY responders.

We created two YouTube videos, that take the viewer through a step-by-step process of registering for the September 11th Victim Compensation Fund and of applying for the WTCHP's Survivor Program, respectively.

For the entire grant period, we participated in: all NIOSH grantee meetings; all but one WTCHP General Responder Consortium outreach coordination calls; all DSNY Outreach Work Group calls; the majority of Work Group for Outreach to Non-English Speakers calls; all WTCHP Survivors Steering Committee meetings; all WTC Health Registry Community Advisory Board meetings; and our PI participated in the majority of WTCHP Responders Steering Committee meetings.

We engaged in productive collaborations with our fellow grantee organizations -- DC 37, NYCOSH, Inner City Fund, Single Stop USA and Voices of September 11th.

We provided input to NIOSH on WTCHP facts sheets, on the NIOSH video testimonials, on the need for WTCHP to increase ease and accessibility in enrolling in the program by creating a smartphone app and an online application. NIOSH did launch an online application in the second half of the grant period. From our discussions, we believe that NIOSH understands the importance of offering a phone app in the future.

One of our outreach fliers, the "3 WTC Programs Explained" flier has been used for outreach by at least two other grantees and has been adapted by the Mount Sinai Clinical Center. NIOSH has created its own version and is awaiting approval to distribute.

Below, we provide greater details on the methods we used with respect to our major projects in the section on Results/Accomplishments. This section also includes a discussion of limit factors or challenges we encountered in our outreach efforts.

V. Results and Discussion/Conclusions by Major Project:

- 9/11EA Outreach Work with NYC Community Boards

New York City's Community Boards are the most "grassroots" level of City government. Made up of 50 unsalaried representatives per district, community boards play a key role in ensuring the quality of life of their districts. For more information, see:

<http://www.nyc.gov/html/cau/html/cb/about.shtml>

For many years, 9/11EA has enjoyed good collaborative relationships with the three Lower Manhattan Community Boards – CB 1 (all of which is located in the NYC disaster area, CB 2 (half of which is in the NYC DA), and CB 3 (more than half of which is in the NYC DA). Our first forum, the WTC Health Forum, was held on June 3, 2013, was co-sponsored by the three Lower Manhattan boards and we invited Brooklyn Community Board 6 (most of which is in the NYC DA).

The purpose of the forum was to educate community leaders and others about the WTC Survivor Program and to introduce Drs. Reibman, Levy-Carrick and Trasande. The key message for the June 3rd WTC Health Forum for Community Boards was: the WTC EHC is the 9/11 Center of Excellence for residents, students and area workers. The physicians, who combine compassion with cutting-edge WTC expertise are our most compelling argument for survivors to enroll in the WTCHP, rather than continue to be treated for 9/11 health problems by non-WTCHP physicians. In addition, we wanted to enlist board members as ‘outreach partners’ in their respective communities and give them a sense of being stakeholders in the program. We had 42 attendees, most of whom were survivors. Others included staff from the offices of Senator Gillibrand, US Representatives Maloney and Nadler and City Council member Margaret Chin attended.

In the run-up to the June 3rd forum, and for the entirety of the grant period, we presented and distributed WTCHP information to at least 7 meetings of each board’s relevant committee, and to at least 8 Full Board meetings. At least 520 postcards and informational flyers were distributed at these meetings. In addition, we have continued to provide the offices of CBs 1, 2 and 3 with materials, first in English; later when the WTCHP “Were you there?” postcards were made available in Spanish and Chinese, we made sure that each board office had those as well.

Challenges:

Our main challenges for this outreach have been the typical ones for the survivor community – the early and ongoing official denials that the disaster posed a potential threat to health, the near absence of WTC research on survivors, the absence of a specialized treatment program until 2007, etc. Those who became sick from their exposures sought care from private physicians, with varying results.

Given that much of our work is focused on New York City-based survivors, we are competing with many other pressing concerns and issues as we try to push an outreach message more than a decade after 9/11.

Getting our message out has been especially difficult in CB 3, which represents the diverse neighborhoods of the Lower East Side and parts of Chinatown. Our challenges stem from multiple factors, but a key factor was the exclusion from eligibility of most CB 3 neighborhoods

from the EPA's WTC Cleanup Program and from the WTC Health Registry – which reinforced official reassurances that there was no impact to the area. We have encountered skepticism that residents could be suffering from 9/11-related health problems. To cite an additional factor that has become more important over time, these neighborhoods, especially the Lower East Side, have undergone widespread gentrification in the last 13 years, which has resulted in the displacement of many of the residents who resided or worked there on 9/11.

Progress:

We have made progress in making the case for complementary treatment – staying with your private physician, but bringing your WTC health problems to the Center of Excellence where you will receive the best specialized care.

We made progress toward getting the attention of community board leaders, who have become a source of referrals and some of whom have become active stakeholders in the program. Because of our ongoing presence at community board meetings, we keep the WTCHP fresh in members' minds and when there are WTC health-related questions, we are turned to as a trusted authority.

We made progress countering skepticism in CB 3 by recruiting a Lower East Side resident to speak about WTC health impacts to her children and a CB 3 member to speak about the community's need for the program.

- **9/11EA Outreach to NYC Public Housing Residents in the NYC Disaster Area:**

In late April of 2013, 9/11EA had a meeting with the Deputy Director of the Family Services Dept. of the New York City Housing Authority, along with an Administrator in the Family Services Department. The goal was to explore strategies to reach out to residents and staff of NYCHA buildings within the NYC Disaster Area. There was extensive discussion of the WTCHP services, the application process, 9/11EA's partnering with Single Stop to conduct outreach, and ways for the Family Services Department to reach residents with WTCHP information. We were asked to hold off on finalizing any plans until July. Unfortunately, when we followed up in June, the Family Services Director responded that due to the impact of federal sequestration on the NYCHA budget, she was retiring and that none of the plans we discussed could go forward. We said we would contact the administrator in the run-up to the 9/11 anniversary to explore much more limited outreach by 9/11EA and Single Stop, timed for the anniversary. The Family Services Director agreed; however, when we tried repeatedly to re-establish contact with the administrator in August, we got no response. In early October, she emailed us to say that she was about to go on vacation. We emailed her again upon her return but heard nothing further.

Challenges:

The best way to ensure that WTCHP and VCF information would be seen by hundreds of thousands of public housing residents was to gain the cooperation of NYCHA administrators. However, shifting priorities in big municipal agencies can quickly unsettle any plans.

Progress:

When we reported this at a NIOSH grantee meeting, it was suggested that we press for information about both the WTCHP and the upcoming VCF deadline to be included with the rent bill sent to every tenant household. 9/11 Health Watch and WTC Health Coordinator Jeffrey Hon pressed this request with the City. Jeffrey Hon worked with us on the appropriate messaging, which was reviewed by Terry Miles, WTC EHC Administrative Director. The text of the rent bill insert provided a short list of WTC conditions, with the notable inclusion of “some cancers.” Notices about the WTCHP and VCF in English, Spanish and Chinese, were placed in the September rent invoices of all 625,000 NYCHA tenants.

- 9/11EA Outreach to Parents of Affected Children & Students

9/11EA has worked over the years to ensure that Lower Manhattan school parents are informed about the WTC pediatric program. We approached WTC Health Coordinator Jeffrey Hon to persuade the NYC Department of Education to send emails to the parents of public school students re: the VCF deadline and the availability of health care at WTCHP. The Department of Education agrees to a letter signed by the Chancellor, but instead of an email blast to parents, it sends the email to principals, allowing them to decide whether to share information with parents. On September 10, 2013, emails go from the office of the Chancellor to 1700+ NYC Public School principals, regarding the VCF and WTCHP.

Challenges:

At the last minute, the DOE resisted the request to communicate directly with parents. Although many principals received the email, we do not believe that many sent the email to parents. Many principals leading schools on 9/11 have now retired and their replacements do not recognize the need to inform parents about 9/11 health benefits for their children and themselves.

We experienced a similar situation with our approach to Borough of Manhattan Community College to send out an email with WTCHP information to their lists of students attending in 2001 and 2002. Located on Chambers Street, right next to Stuyvesant High School, BMCC is part of the City University of New York (CUNY) system. We got the agreement of high level BMCC administrators to do the email blast, only to be told a week later that the initiative had been rejected by CUNY’s Central Administration.

Progress:

In contrast to our experiences with the DOE and with CUNY, we worked with the Pace University Dean of Students and the head of the Pace Alumni Association on a successful effort for the university to email more than 9000 alums with WTCHP information.

Under 9/11EA's current outreach contract, we are planning to approach the de Blasio Administration with the same request. We hope to make good progress.

- **9/11EA's Use of the September 11th Victim Compensation Fund (VCF) registration deadline to Promote the WTCHP**

In the course of our work, 9/11EA had encountered a phenomenon among affected residents who seemed willing to indefinitely postpone enrolling in the WTC Survivor Program, but who could not live with themselves if they failed to apply for the VCF and thus deprived their families of financial compensation. We set out to use the first VCF registration deadline (October 3, 2013) to promote the WTCHP (and we suggested on WTC Responder Consortium Outreach calls that other groups do the same).

We did interviews with most of the downtown community print and online media outlets, publicizing both the deadline, the advantages of WTCHP enrollment, and also to announce our YouTube video on how to register for the VCF. These media included the Downtown Express (circulation approx. 40,000), DNAinfo (with 1.5 million unique visits per month) and the Battery Park City Broadsheet (estimated 10,000 placed in residential buildings below Canal Street and circulation of eBroadsheet daily edition of 5,000).

When members of the Independence North Tenants Association reached out to 9/11EA with questions about the VCF and its deadline, we offered to do a forum in the IPN community room. The "Special VCF and World Trade Center Health Program Information Session for IPN Residents," took place on September 19, 2013, co-sponsored by 9/11 EA and IPN Tenants Association and was attended by a capacity crowd of 80 residents. We presented on the VCF and WTCHP, and ran out of Survivor enrollment forms, '3 programs' fliers and VCF Interim Registration Forms. We brought an additional 150 pieces to IPN in the days following the forum.

On September 20, 2013, 9/11 EA released the instructional video "How to Register for the VCF in about 5 minutes." The voiceover advises survivors to enroll in the WCTHP as follows: "If you have been treated at the World Trade Center Health Program, mark yes. If not, mark no. But you should seriously think about enrolling in the World Trade Center Health Program which provides high quality, expert care from doctors who know the most about how 9/11 affected the downtown community. Once a doctor at the World Trade Center Health Program has certified your medical condition, then you have met the VCF's proof requirement for that

condition. For more information on the World Trade Center Health Program, visit our website – 911ea.org.”

The video was sent to all grantees, all members of the WTC Survivor Steering Committee (68) and was uploaded to YouTube. Press release sent to all downtown community news outlets. The video was posted to Manhattan Community Board 1’s Facebook page. The video has 752 views on YouTube

Challenges:

Our chief challenge is how to motivate sick survivors to enroll in the WTCHP, breaking through their reluctance to consider that their health problems may be 9/11-linked or their ‘default position’ of getting care from non-WTC-specialized physicians for conditions that are WTC-related.

Progress:

As the NIOSH/WTCHP enrollment data for Fall/Winter 2013 show, the VCF registration deadline was a major driver of applications to the WTCHP across eligible populations. The strategy of using the VCF deadline as an opportunity for outreach and education about the WTCHP was effective.

- 9/11EA’s Outreach to DSNY responders and survivors

9/11EA’s first DSNY-related outreach effort took place at a May 2013 meeting held by SEIU Local 444 Sanitation Officers Association at their training Floyd Bennett Field center. We were invited to address questions about survivor eligibility to the WTCHP and VCF-focused meeting, and were introduced to Joseph Mannion, President of the local.

In our own internal discussions, we discovered that our outreach staff had DSNY responder contacts that pre-existed our grant. When we learned from a discussion with Scottie Hill and other Responder Program outreach staff that DSNY participation in WTCHP was very low relative to DSNY’s participation in 9/11 rescue, recovery and cleanup, we decided to explore what we could contribute to this outreach.

In the Fall of 2013, we had a number of conference calls with a DSNY retiree, who was a responder and a longtime friend of our WTC Volunteers Outreach Coordinator. He agreed to distribute materials and we agreed to design a webpage on our website, along with two flyers customized for DSNY responders and survivors.

In early November, Annie Lok of the WTC Health Program Data Center, initiated twice-monthly DSNY Work Group calls and 9/11 EA volunteered to research information on DSNY Fraternal organizations. We gave our written report to Annie Lok.

In November /December 2013, 9/11 EA begins to design a new webpage on the 9/11EA website specifically for Sanitation workers with links to both survivor and responder applications. In designing the page, we secured photographs from the project “Chasing Sanitation” to ensure that when DSNY employees visit our site, they would feel a sense of being specifically addressed, i.e., see that they were in the right place.

In mid-Fall 2013, we contacted Philip Crowe, Administrator of DSNY’s Medical Division/Occupational Health Clinic, to ask for his assistance in reaching DSNY workers. We sent a follow-up letter with samples of the WTC DSNY Fact Sheets. On December 10, 2013, our Project Manager had a follow-up call with Crowe who said that he and clinic staff are aware of the WTCHP and refer to it as needed. He did not seem interested reaching out to active or retired DSNY responders with information on the WTC Monitoring Program.

In October of 2013, we discovered through one of our DSNY retiree contacts that information about the VCF registration deadline was inserted with pension checks. We were dismayed that an opportunity had been lost to include WTCHP information and our Principal Investigator brought this information into a Responders Steering Committee meeting discussion of low enrollments among DSNY responders. One outcome of this discussion, which also included a report on the DSNY Work Group from Annie Lok, was a request by the Committee Chair to the WTC Health Registry that it focus its Treatment Referral Project on its DSNY enrollees.

Frustrated with our lack of response from official channels, we stepped up our efforts through informal channels. On March 17, 2014, we located the DSNY Emerald Society (Fraternal Organization) as they were mustering up to enter the St. Patrick’s Day Parade. During the period pre-march, when the marchers and bands were assembling, 9/11 EA distributed WTCHP information to sanitation workers, police officers, corrections officers and other officers that were on duty during 9/11, some of whom were not aware of the program. At least 100 pieces were distributed. We were able to speak with Garry Resnick, then-Outreach Director for the Mount Sinai CCE, about a lack of program awareness we’d encountered among some Department of Corrections officers at the parade. He said he would do another approach.

In early spring of 2014, we contacted Belinda Mager, Assistant Director of Public Information-NYC Department of Sanitation who is in charge of the DSNY Newsletter. In the course of a phone conversation, Ms. Mager agreed to receive information about the program which we sent along with our customized DSNY fact sheets. Several weeks later, we receive a phone call from a DSNY worker who had seen an article about the WTCHP in the newsletter and wanted additional information. We called Ms. Mager and got confirmation that WTCHP information had run in the Spring 2014 newsletter, which was distributed to all of the garages in the city and reached approximately 10,000 employees.

Challenges:

DSNY institutional support for outreach efforts has been uneven. As a result, many DSNY affiliated responders are not aware of their eligibility for WTCHP treatment, and especially for monitoring. In addition, the efforts of DSNY-affiliated responders are often in the shadow of those of firefighters and law enforcement in the media.

Progress:

In order to supplement outreach efforts to DSNY responders and survivors through official channels, 9/11EA has found that informal networks can sometimes succeed in a context where formal networks do not quite reach segments of rank and file members. We worked to grow informal networks through social media, especially Facebook pages. We created customized materials that spoke directly to DSNY responders and survivors. In addition, we have created a page on our website targeted to employees of the Department of Sanitation with content customized for them, and that recognizes their roles as responders as well as their daily contribution to the life of our city.

We were able to contribute information and insights to the DSNY Work Group, to the Responders Steering Committee discussion of DSNY enrollment levels, and to Garry Resnick in ways that informed outreach efforts to this population going forward.

- 9/11EA's Video to promote WTCHP

9/11EA had planned to produce a video to promote WTCHP that would feature three downtown mothers speaking about why they brought their children to the WTC Pediatric Program (part of the WTC EHC at Bellevue Hospital). The "3 Downtown Moms" would be an upbeat affirmation of the excellent care and the great progress toward recovery for their children. We believed we could recruit one mom per language – English, Spanish and Chinese, especially given that we knew the English and Spanish-speaking moms and their stories. In addition, we had spoken with WTC EHC Administrative Director Terry Miles about a Chinese-speaking mother. Unfortunately, when it came time for us to get a timeframe for a video shoot, one mom backed out and the other dropped out of contact entirely. When Terry approached the Chinese-speaking mom, she quickly refused. Midsummer 2014, Terry did one more review of possible candidates but when he found no one willing, we abandoned the idea.

When a NIOSH/WTCHP staffer suggested that it would be helpful to have a video, like our VCF clip, that explains to survivors how to enroll in the WTCHP, we decided to do just that.

Our second video product, "How to Enroll in the WTC Health Program," was an instructional video which takes applicants through the survivor's English enrollment form step-by-step in just

under 7 minutes. We used the WTCHP Survivor enrollment form as the visual foundation of the first part of the clip, which shows the five-page application being filled-in on screen, accompanied by clear instructions from the narrator.

The second part of the video addresses the requirement for supporting documentation and best examples of that documentation. The third section describes how to submit the application, and the last section explains where to go for help.

Challenges:

The principal challenge for any video product that addresses 9/11-related health problems and the care provided by the WTCHP is to capture and hold the attention of survivors and to motivate them to consider enrolling. We believe the only viable approach is upbeat.

The WTCHP Survivor enrollment form and its documentation requirements poses a challenge to many survivors and it is not the case that all prospective survivor enrollees have contact with grantee organizations who can help them address any barriers. Many survivors keep private that they believe they have 9/11 health problems and that they are considering enrolling in the WTCHP.

In addition, we had technical challenges, chiefly, to make a product that looked seamless and simple using software that involved superimposing the many layers of the graphics we used. The video was quite complicated to edit, as was the integration of the voiceover narration and the work of synchronizing words with visuals.

Progress:

We have received very positive feedback on “How to Enroll in the WTC Health Program,” that it highly accessible, making the enrollment process easier to understand and to complete. The video currently has 61 views, without our having done a press announcement. Under our contract, we have offered to provide the video to other NIOSH outreach contractors, and several have asked us to customize it with their branding and contact information. In addition, under the contract, we are producing a version in Spanish. When we complete the Spanish version, we will announce to the downtown and Brooklyn community media that both English and Spanish versions are up on YouTube, and we will look for other ways to promote and cross-promote it.

- 9/11EA’s Outreach to Survivors at Lower Manhattan Greenmarkets

In late July 2014, 9/11 EA contacted the Director of Public Information at Grow NYC to see if we could obtain permission to distribute WTCHP information through the various greenmarkets. Customarily, each market has a special table set up with free health and/or nutrition-related

information. In addition, we hoped to have our own table at the Union Square Greenmarket (the largest and most frequented) the day before the September 11th anniversary.

We had also planned to hand out WTCHP postcards in person at the Staten Island Ferry Greenmarket. However, due to Homeland Security protocols for the Ferry, there is only one farmer and no one but he or Greenmarket staff can distribute materials.

Greenmarket Public Affairs asked for samples of our postcards and other handouts and approved us for a tent and table at the Union Square Greenmarket for September 10, 2014. The market was quite crowded with many noting our posters and WTCHP banner. Six people stopped by our table to talk and we provided information and instructions for enrollment to several.

In September of 2014, 700 WTCHP postcards in English, Spanish and Chinese, were provided to the Greenmarket Director of Public Information (DPI), whose staff has continued to distribute them through December 2014, at major Lower Manhattan greenmarkets, including the one at Staten Island Ferry, at Washington Market Park, City Hall Park, Albany and Greenwich, Bowling Green, Union Square Park, and Brooklyn Borough Hall. We ourselves have continue to bring WTCHP postcards to many of these locations.

Greenmarkets have been closed in January and February 2015, but we have sent the Greenmarket DPI 250 English and 50 Spanish WTCHP postcards for distribution as soon as the markets resume.

Challenges:

Survivors are for the most part unwilling to attend 9/11 health-themed events. In addition, at this point, some survivors, especially those who worked in offices downtown on and in the immediate aftermath of 9/11, are dispersed and work and reside in other neighborhoods.

Progress:

Greenmarkets in the NYC Disaster Area are frequented regularly by many residents and workers. The Union Square Greenmarket is frequented by residents and workers from all over the city. We have established a good relationship with the DPI and will continue to work with her to ensure the availability of WTCHP materials, and to get a Union Square tent/table for the upcoming 9/11 anniversary.

- 9/11EA's Use of Social Media

It is still the case that many Lower Manhattan families and area workers are simply not aware that the WTCHP exists, or that certain health problems have established links to 9/11. More than a decade after 9/11, it is difficult to push our message re: the availability of care to those who are

sick as a result of 9/11. Doing so in context of New York City's media market, one of the most complex and diverse in the world, adds to the difficulty.

We believe that social media offers new opportunities to do survivor outreach and education, which we continue to explore. We have used the appropriate social networking tools to reach prospective enrollees, in NYC and beyond. For some affected survivor populations, such as students who were attending several high schools bordering the southeastern edge of the WTC site on and after 9/11, social media may well be the only means of reaching them.

Website www.911ea.org

We have frequently updated our website in an effort to effectively promote the World Trade Center Health Program. As an important educational tool, we use web content to reflect what is happening in the World Trade Health Program, especially with respect to the addition of new conditions to the WTC list, to guide prospective enrollees through the application process and to help readers understand related research and other topics such as the VCF.

Progress

We received the standard \$10,000 per month Google Ad Grant to promote our mission and initiatives on Google search result pages. This allowed us to create a number of short 3-line ads that come up randomly on Google searches that include our keywords. We found that our ads framed as questions (such as "Are you confused about 9/11 health care?") seemed to have better CTRs (Click Through Rates).

Challenges

One barrier we encountered is that the "non-profit" ads are displaced on a search whenever a paid ad is due to run. Another barrier is that Google Ad Grants cannot be used to promote videos of any kind, so we are using other means to promote our videos.

Facebook <https://www.facebook.com/911ea>

We have learned over time that unless we have a strong combination such as the anniversary of September 11th plus a compelling image, or we ask people directly to like our Facebook page, paid advertising is the only way to reach and grow an audience (Likes) on Facebook. We have been advertising on Facebook and have found that increase in Likes is directly proportional to the amount spent. Currently we have 1,122 likes.

Challenges

A big barrier with Facebook ads is that they cannot be more than 20% text. This means we have had to redesign our graphics which are very text based. Currently, we are unable to advertise our "How to Enroll" video on Facebook, since the still frame that Facebook grabs is almost ALL

text. The video is up on 9/11EA's Facebook but cannot be "boosted" without Facebook's help, which is a current priority. We will need to solve this problem with Facebook advice.

Progress

Very recently Facebook changed its management for pages and although there was a small learning curve, reporting now seems to be more powerful, flexible, and focused which will help us in having more successful advertising. It has also made it easier to go after populations by region. We have now targeted nearby states.

Twitter <https://twitter.com/911ea>

We have been using twitter to stay in touch with existing followers, reach new ones, make announcements, link to press releases and share important news in real time.

Challenges

Since 9/11 health issues tend to be a dormant subject a good part of the time, our greatest challenge was to ascertain what could be used as interesting, relevant content.

Progress

When NIOSH gave us the idea to tweet about the monthly health issues, for example, colon cancer screening, it opened up a new door for us. We also have begun to tweet about where we place WTCHP postcards and other materials, in libraries and churches.

We have 172 followers and follow 781, and have tweeted 438 times. Our followers include elected officials, media, unions, schools and other community-based organizations.

- 9/11EA's Outreach to 9/11 Disaster Relief Volunteers (by Jennifer Spano, WTC volunteers outreach coordinator)

Our outreach target group was 9/11 volunteers from across the country.

These were volunteers who worked in disaster relief in the NYC Disaster Area during the rescue, recovery and clean-up efforts. Included were volunteers from the Salvation Army, American Red Cross, St. Paul's Chapel and other groups who worked at or in the vicinity of Ground Zero, the Medical Examiner's Office, and the Staten Island landfill.

Outreach was conducted in multiple ways:

Email

I utilized existing email lists dating back to the time of the Ground Zero recovery and cleanup. Other emails were culled from scraps of paper, notebooks and personal documents kept after the site closed (~600).

I possessed a large amount of photos of volunteers that were taken at the time of the disaster. I scanned this set of photos and sent individual photos to the respective people as a way of breaking the ice from the time that we worked together 12 and 13 years ago (~150).

In the same email, I was able to send an invitation to receive program flyers and to begin a conversation about the health program. This was successful in many cases. Most recipients asked for the follow-up and received the flyers explaining the WTCHP, the Nationwide Provider Network, and the distinction between the three programs that responders and survivors often confuse: the WTCHP, the WTC Health Registry and the Victims Compensation Fund.

Internet and Facebook

For those people whose emails were missing or had bounced, I researched those whose email addresses were missing or ‘bounced back’ on the Internet, on Facebook and LinkedIn. This effort was successful in the case of approximately 40 contacts.

In addition, I was able to correspond with volunteers on 2 Facebook pages:

- The already-established Facebook page, “9/11 GZ Fellowship on Face Book” (sic). The group is a mixture of the 9/11 Community, with volunteers, responders, family members and survivors, and has 197 members.
- A pre-existing Yahoo group that is still active and has 93 members who are mostly volunteers.
- A new Facebook page that I started called “9/11 Volunteers Health Forum.” While it focuses on volunteers, the entire 9/11 Community is invited to discuss health issues, and so some responders, family members, and survivors have also joined. This group has 135 members.

The Health Forum, the Fellowship and the Yahoo Group have been good vehicles for 9/11 community members to post messages and share information. I would periodically post relevant information, especially as deadlines were approaching.

Phone calls

I’ve also made phone calls to those for whom I had no other contact info, those who requested it and for sensitive issues or follow-up discussions. (~25).

NVOAD Conference

In May, 2014 I attended the annual National Volunteer Organizations Active in Disaster (NVOAD) conference in Indianapolis. There I was able to reconnect with some former GZ volunteers attending the conference, to work at the booth of another grantee group, the Inner City Fund, and interact with attendees, to network with other groups that had sent volunteers to NYC

to work in 9/11 disaster relief and to attend workshops. (Direct outreach to ~100 within conference attendance of ~400.)

Through these activities I was able to distribute postcards and hand out business cards, make new contacts, renew old contacts, and identify other groups who may be able to spread the word about the availability of WTCHP monitoring and treatment..

Post-conference, I followed-up with certain renewed contacts, including a Salvation Army officer, who was able to distribute our information and flyers to his entire division (~500 to 600).

9/11 Anniversary Events

During the 9/11 anniversaries of 2013 and 2014, I was able to see my many friends and contacts in the 9/11 community and to attend several gatherings that occur each year:

The St. Paul's Annual Volunteer lunch is attended by a mixture of volunteers, but mostly those who worked the relief effort at St. Paul's Church, and by some responders (~35).

The annual 9/11 open house at the apartment of a couple who host a large number of people over the course of the anniversary day and night, attracts a mix of volunteers, responders and family members. I was able to speak with about 100.

In 2014, I attended the World Trade Center Survivor's Network Luncheon to make contact with some new people (~15). The Survivors' Network had always included the volunteers and offered them an opportunity to attend the Commemoration Ceremony Linda Gormley, a board member of the organization and the person who always coordinated the volunteers along with the survivors, took some flyers from me to distribute and 9/11EA's contact information was posted on their website.

Once the 9/11 Memorial's website became open to registrations, I was able to get emails to some former contacts who worked as 9/11 volunteers (~5).

I also participated in some of the ongoing conference calls, including the WTCHP Outreach Coordination Call and the DSNY Outreach Work Group.

Challenges:

The barriers to reaching people were both logistical and emotional

Logistical

Finding tens of thousands of people who volunteered, more than a decade after 9/11 without the benefit of a major effort by the key disaster relief organizations is extremely difficult.

Emails, Facebook and 9/11-related websites provided some success in tracing contacts, but many volunteers remain unaware of the availability of WTCHP monitoring and treatment. Even for my own lists, the grant ended before everyone could be contacted.

Emotional

The good news is that there were only a limited number of non-responses from people whose emails did not bounce or whose Facebook messages went into their Inbox.

Some volunteers feel that so much time has elapsed since 9/11 that they are not entitled to “complain” about their health or to connect their health issues back to 9/11. Some want to forget 9/11 and so cannot focus on the potential health impacts.

Ego, machismo, shame and survivor’s guilt have also factored into the resistance to getting help. Some feel unworthy, believing that only firefighters, police officers or other “established” heroes are entitled to care. Some are too overwhelmed in general in their lives or in remembering the work at Ground Zero to face the paperwork.

Finally, many have moved on to relief work in the context of other disasters.

Progress:

My outreach efforts were effective in reaching more than 1200 volunteers. My messaging to counter unworthiness, to explain that sick volunteers were also deserving of care, to explain that enrolling in the monitoring program was essential for proper health surveillance of the whole population of responders, was well received.

A point of note: Throughout my outreach work, I was told repeatedly by volunteers that I was the only one who had contacted them. I would have thought that the organizations who hosted these volunteers would have sent them some information about the Zadroga Act and the benefits it provides for them. However, this did not appear to be the case.

List of community meetings, not addressed in the major projects sections, at which WTCHP materials were distributed by 9/11EA:

Lower Manhattan First Aid Forum, sponsored by Community Board #1's Quality of Life Committee, on Thursday, February 21, 2013

NYC Health and Hospitals Corporation Office of Patient and Employee Safety Wellness Fair, on May 13, 2013

Breast Cancer Awareness Week, Tabling with Priya Pasram of the SUNY Brooklyn WTC Center, on May 15, 2013

Father Mychal Judge Walk of Remembrance on September 8, 2013

Voices of September 11th Annual Day of Remembrance Information Forum on September 10, 2013

2013 Annual Anniversary Lunch for Friends of St. Paul's Chapel World Trade Center Relief Ministry on September 11, 2013

September 11th Community Remembrance at Manhattan Youth Downtown Community Center, on September 11, 2013.

Parallel Stories: The World Trade Center and Battery Park City, on September 11, 2013 (Tabling)

The 12th Annual Battery Park City Block Party, on September 28, 2013 (Tabling)

The Lower East Side Power Partnership Community Night on November 7, 2013

Town Hall Forum on the Fate of the South Street Seaport on January 13, 2014

WTC Neighbors meeting at Assembly Speaker Sheldon Silver's office January 23, 2014

NY Rising Community Reconstruction Program Lower Manhattan Public Meeting on March 1, 2014

Saint Patrick's Day Parade on March 17, 2014

Lower Manhattan Public Engagement Meeting/ New York Storm Recovery Resources Center on May 21, 2014

Father Mychal Judge Walk of Remembrance on September 7, 2014

September 11th Community Remembrance at Manhattan Youth Downtown Community Center, on September 11, 2014

9/11EA Outreach Statistics

(Note: All figures pertain to Survivors unless "R" for Responders is noted)

September 2012 through December 2013

DIRECT OUTREACH

Event	#Attend	# Fliers	#Applic.	#Engaged
VCF Information Forum	200	25		4
PACE First Aid Forum	50	50		
Tribute Center Docents	15	15		
Meeting with NYCHA	2	2		3
SEIU Sanitation Officers	40 R		1	1 R
NYC HHC Wellness Fair	250	200	15	15
Kings County Hosp. Tabling	100	15	2	
9/11EA Health Forum (6/3)	42	42		
Father Mychal Judge Walk	300 R,S	94		
St. Paul's Chapel Lunch (9/11)	40 R	40		
9/11 at Manhattan Youth	55	N/A		
9/11-Museum of Jewish Heritage	75	50	5	
9/11- Johnnie and Denise Gathering	100 R,S	40		50
IPN meeting WTCHP and VCF	80	180	10	25
Flag Folding Ceremony	50 SR	15		

BPC Block Party	200	60		30
LES Power Partnership	100	75		5
Brooklyn CB 2	90	300		
Sasha Green – UFT	1	30		
Direct Total: 19 events	1790	1233	33	133

September 2012 through December 2013 cont'd
INDIRECT OUTREACH

Event	Method	Number Reached
Brochures to Women's Centers	Mail info	30
PACE email to Alumni	Email blast	9200
Smoking Cessation group	Mail info	30
Kentucky Baptist Convention, R	Email blast	4500 Volunteers
Downtown Libraries	Drop off info	100
Article in Broadsheet 5/31	News article	15,000 Circulation
Article in Broadsheet 7/26	News article	15,000 Circulation
NYC Dept of Education	Email blast	1700 Principals
NYCHA -Rent Invoices	Mailed with invoice	625,000 Tenants
WTC Disaster Relief Volunteers, R	Email blast	601 Volunteers
Salvation Army, R	Email blast	16 SA Staff
WTC Residents Coalition	Email blast	25,000 Residents
Article in Downtown Express 9/12	News Article	40,000 Circulation
Article in Broadsheet 9/25	News Article	15,000 Circulation
Indirect Total: 14 Events		Reach: 751,177

January 2014 through February 2015

DIRECT OUTREACH

Event	#Attend	# Fliers	#Applic.	#Engaged
Seaport Town Hall	100	5		1
St. Patrick's Day Parade (NYC)	N/A	100 R		
NVOAD Conference	400 R	100 R		
Greenmarket Tabling	500	50	1	1
Greenmarket Drop-off	N/A	250		
BPC Block Party	200	25		3
Direct Total: 6 events	1200	530	1	5

INDIRECT OUTREACH

Event	Method	Number Reached
Hatzolah Volunteer Ambulance	Email info	35
Downtown Libraries	Drop off info	615
Sheldon Silver's office	Drop off info	15
DSNY	Newsletter Article	10,000 employees
DSNY/SEIU Supervisors	Sent info	100 sets
"Post" NVOAD Conference	Sent info	550
WTC Residents Coalition	Email blast	25,000 Residents
Ad in Downtown Express 9/2014	Ad for WTCHP	40,000 Circulation
Ad in DNAinfo.com 9/2014	Ad for WTCHP	70,000 Enews Circ.
Grow NYC	Sent info	800 cards
Indirect Total: 10 Events		Reach: 147,115

9/11 EA Outreach Grand Totals for Entire Period of Grant

Direct Outreach – 25 Events 2990 Attendees 1763 Fliers 34 Applications 138 Engaged

+ Manhattan Community Boards - 25 Events 520 Fliers

Total Direct Outreach – 50 Events 2990 Attendees 2283 fliers 34 Applications 138 Engaged

Total Indirect Outreach – 24 Events 898,292 Reach

Social Networking:

Twitter 172- Followers We Follow -781 Tweets- 438

Facebook 1122 Likes

YouTube VCF Video - 752 Views How to Enroll (English) 61 Views

Individuals given enrollment assistance: 33

StuyHealth Outreach to Young Adult Survivors

StuyHealth's Mission:

StuyHealth (SH) endeavors to reach 9/11's young adult survivor population, many of whom are dispersed nationwide, with a heavy reliance of social media outreach and other web-based efforts.

SH Aims:

One of our primary aims in the grant cycle was to increase awareness about the Nationwide Provider Network (NPN) among our cohort, in addition to the NYC-based program. The NPN was still in its early stages when we began work on the grant-funded project and our plan was to learn what we could about it and focus on making sure SH members living outside of the tri-state area knew there were WTC health services available to them wherever they lived. In the process, we provided ongoing and important feedback to the NPN about concerns facing our demographic, which has improved service delivery. Throughout the grant, we have continued to assist local survivors in accessing care at the NYC Centers of Excellence.

An additional key aim for this grant cycle was to update our web presence and make sure that our website had the look and feel of professionalism and legitimacy and that our information was accurate and up-to-date. We launched what we feel is an extremely professional, informative, comprehensive and understandable website.

We also aimed to make, and succeeded in making, a PSA advertising the WTCHP that was geared towards members of the survivor population that can't handle more serious, depressing reminders of the attacks.

SH Methods/Activities for Outreach work:

September through December 2012

- Reunion Event: Conducted outreach at the Stuyvesant Class of '02 Reunion – November 23, 2012, attended by over 350 alums. Had detailed discussions with approx. 30 re: WTC HP eligibility and the application process. Stocked and managed a table with WTC EHC brochures and promotional items (more than 50 taken, especially the pens).
- Posted on SH Facebook page re: 9/11 health news, including addition of cancers, an asthma study, potential sequester cuts, etc.
- Answered questions from SH members
- Updated SH website

January through April 2013

- Posts on FB: 3 Facebook posts on SH page, 2 on the Stuy Classes '02-'05 page, ranging from calls for participation in NIOSH testimonials project to mental health services after the Boston Bombings.

- Writing copy for future social media push with the help of Thomas Mei
- Redesigning StuyHealth logo for a more professional look that will be easier to brand things with.
- Added new sections to SH website
- Recruited new SH members to become more active participants in SH and the WTC HP SSC.
- Email dialogue with SH members about the application process, as well as answering questions about what kinds of illnesses we're seeing in the Stuy community.
- Placed an ad in the Stuyvesant alumni newsletter, the Alumni Spectator that directs people to SH website and Facebook group.

[SH outreach resulted in at least 3 SH members completing applications to WTC HP, 1 is in the process of re-enrolling.]

May 2013 - August 2013

- During this period, our group grew by seven members (bringing the total to 436), and we assisted as many with questions about their WTC Health Program applications.
- Posted 5 updates to our website and 10 updates to Facebook, with supporting posts shared on personal pages and Twitter. In our posts we clarified information about acceptable forms of proof for the health program application sent out links to help former students find transcripts and other acceptable forms of proof that they were in lower Manhattan in 2001/2002.
- We also shared information about three forums, meetings and events of interest to our cohort, and posted information about how to navigate the application process for the newly functional National Program.

September – December 2013

- Submitted comments on NPN handbook, both on November 1, 2013
- Emailed NIOSH re: LN's experiences with and concerns about the National Program Network.
- Group grew by 16 members (bringing the total to 452)
- Helped answer specific 9/11 Health Program questions for more than 10 members. (The VCF registration deadline, which occurred at this time, was helpful in that it encouraged people to look into the other 9/11 programs and assess whether they qualified.)
- More than 20 people contacted us or approached LN personally for information about the differences between the programs and most of those people, many of whom were complaining of conditions such as GERD and asthma, were encouraged to look into the health program.
- We also posted 4 updates to our website, 11 updates to Facebook, and answered questions in our comment feeds and those of the supporting posts on personal pages and Twitter.
- We sent a stack of informational materials to the Stuy '03 reunion, which had well over

200 attendees

- Began a mailing list, which has 161 recipients and growing. Our first newsletter went out in October.
- Started plans to overhaul our website with the hopes of creating a clearer navigation experience and better social media integration. We began work on the new site in December.

Jan 2014 – September 2014

- Posted 4 tweets, 17 Facebook update
- Began developing our video concept, aiming to make something light enough in tone that even people who don't like talking about 9/11 could stomach watching
- Did all the pre-production work leading up to the video shoot including writing, casting, hiring a crew, and sourcing equipment
- Launched our re-designed logo with the help of a graphic designer
- Worked with a web developer for months to perfect the look and design of our new website
- Wrote all the content for the new site and worked extensively to ensure it was easy to navigate. We focused on making sure we had pages that would address the questions we get more frequently about WTCHP services and would stress the extent of the NPN's reach.

September 2014– December 2014

- After months of preparation, including writing pages, working with a web designer and a graphic designer, and acquiring information, photos, and feedback, we launched our new website on September 12th 2014
- Wrote and produced a video aimed at educating StuyHealth members about the WTCHP, which we released in the week after September 11th. We were able to get Rep. Jerrold Nadler to participate, as well as City Councilperson Laurie Cumbo from Fort Greene in Brooklyn. The video was posted on YouTube and Vimeo.
- To promote the site and video we focused heavily on social media, not just using our own Facebook and Twitter accounts but also asking our members to post on their own pages. We featured the video on our website and got several politicians to tweet about it including Rep. Maloney, Sen. Gillibrand, and Rep. Nadler.
- We made 24 Posts on Facebook, worked to get approximately 20 people to post the new site or video on their personal pages, and tweeted 38 times.
- Our Twitter following rose to 99 followers

Results/Discussion:

Overall:

- NEW MEMBERS: 40 (FB Group), +/- 70 (FB Page)

- FACEBOOK POSTS: 70+
- TWEETS: 60+

Accomplishments:

- Fully re-designed website
- 1 video
- Reached 1000+ Lower Manhattan-based Stuyvesant alumni
- Answered queries about services for 9/11 survivors for 20+ SH members

Challenges/ Progress to address challenges:

Now that it's so many years later, it's becoming increasingly difficult to find new people to reach with information about the WTCHP services. Communities that were never provided with any information about health and safety issues surrounding the 9/11 clean-up are often not interested in hearing about the resulting health issues now. It has been difficult to engage or even to find new communities as a result.

As we've said in past reports, we still believe that the young adult application rates would greatly benefit from a smart phone app designed to facilitate the application process, though finally having a web-based application is a huge improvement.

Beyond just the application process however, an ongoing obstacle for us has been the comparative lack of tech-savvy the WTCHP operates with. From the NPN's love of signature-required Fed-Exes and longwinded phone calls, to the initial difficulties we saw getting people to take seriously a program that required a printed application and xeroxed proof of exposure, we've been fighting an uphill battle. It's important to stress that these create very real barriers for young adults, who are less comfortable with these outdated means of communication and generally prefer to spend less time talking on the phone sorting things out and more time dealing with logistics via the web.

Previously, non-New York residents would lose interest when we explained the offerings of the WTCHP because they could not access the services. Having the National Program available made a huge difference in terms of how receptive people were to our outreach. As the NPN gets its bearings, it's gotten easier to do outreach work for the program. Early on there was very little information about it available on the WTCHP site. We looked to rectify that by dedicating an entire page of our re-designed site to explaining how it works. Nonetheless, there's still a relative lack of official information about what the NPN entails/how it operates. The fact is that the experience of being a patient at the NPN is not similar to that of being at a Center of Excellence, and it's not helpful that the WTCHP appears reluctant to address that fact. The NPN is a major cornerstone of our outreach work – young adults are a widely dispersed population – so we think it's important that there be clear, separate information specifically about the NPN. With that

said, we've discussed many of these concerns with the NIOSH team and feel like a lot of progress has been made.

We're proud of our web re-design, which has made a huge difference in terms of how seriously young adults are taking our outreach, education and assistance. The new website has drastically cut down on the number of simple questions we're asked about the application process, leaving us to assume that the information there is clear and user-friendly.

We've also focused on how to approach young adults about the health consequences of 9/11 without disturbing or panicking them, which is why we chose to make a web video advertising the WTCHP that starts out humorous. As time goes on, some of the denial about what happened is starting to dissipate and SH is seeing an uptick in the number of people willing to admit they want mental health services and other kinds of care, despite the stigma. Also, rising numbers of anecdotal cancer reports among Stuyvesant alumni seem to be making young adults nervous.

As a final note, we've struggled with ways to make WTCHP relevant to young adults year-round, but continue to find that the September anniversary season is the time people are most open to discussing this issue. It's been difficult to keep people engaged year-round and almost feels cruel to remind them of this horrible event or the horrible consequences as they innocently go about their Februaries. We're looking for ways to make this issue more approachable and less disturbing to talk about so that we can do more effective outreach at times of low media interest.

StuyHealth Outreach Statistics Summary

Direct Outreach; 2 events 550 attended
Indirect Outreach -Contacted 10-15 groups re PSA: 5000

Social Media:

Facebook Group - 463 Members

StuyHealth Facebook Page - 100 Followers

Stuyvesant Classes '02-'05 Group - 1226 Members

Twitter Followers - 99 Followers

StuyHealth Mailing List - 167

List of Abbreviations

9/11EA.....	9/11 Environmental Action
BMCC.....	Borough of Manhattan Community College
BPC.....	Battery Park City
CB.....	Community Board
CCE.....	Clinical Center of Excellence
CTR.....	Click Through Rate
CUNY.....	City University of New York
DC 37.....	District Council 37
DPI.....	Director of Public Information
DSNY.....	Department of Sanitation of New York (City)
EPA.....	Environmental Protection Agency
GZ.....	Ground Zero
IPN TA.....	Independence Plaza North Tenants Association
LES.....	Lower East Side
NIOSH.....	National Institute for Occupational Safety and Health
NPN.....	Nationwide Provider Network
NYC DOE.....	New York City Department of Education
NYCHA.....	New York City Housing Authority
NYC HHC.....	New York City Health and Hospitals Corporation

NYCOSH.....New York Committee for Occupational Safety and Health

NVOAD.....National Volunteer Organizations Active in Disasters

RFP.....Request for Proposals

SH.....StuyHealth

UFT.....United Federation of Teachers

VCF.....September 11th Victim Compensation Fund

WTC EHC.....World Trade Center Environmental Health Center

WTCHP.....World Trade Center Health Program