

Bringing Patient-Focused Care and Research to Our Heroes

Stony Brook WTC Wellness Program



Healthcare: WTC Health Program Long Island Clinical Center of Excellence

Education: Sustaining the Legacy of 9/11 Responders in Our Communities

Research: Comprehending the Consequences of 9/11 Response Work and Improving Care



Stony Brook Medicine

WTC Health Program



Monitoring and Treatment

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Commonly Used Terms

LI-CCE: Long Island Clinical Center of Excellence

James Zadroga Act: Legislation signed into law in 2011 that reopened the September 11th Victim Compensation Fund, and provided direct federal funding for 9/11 responder and survivor healthcare

VCF: September 11th Victim Compensation Fund, which allows individuals who suffered physical injury or death as a result of the September 11th attacks (or next of kin) to obtain compensation

NIOSH: National Institute for Occupational Safety and Health, which administers the WTC Health program

CDC: Centers for Disease Control

Comorbidity: The simultaneous presence of two chronic diseases or conditions in a person

LRS: Lower respiratory symptoms

GERD: Gastroesophageal reflux disease

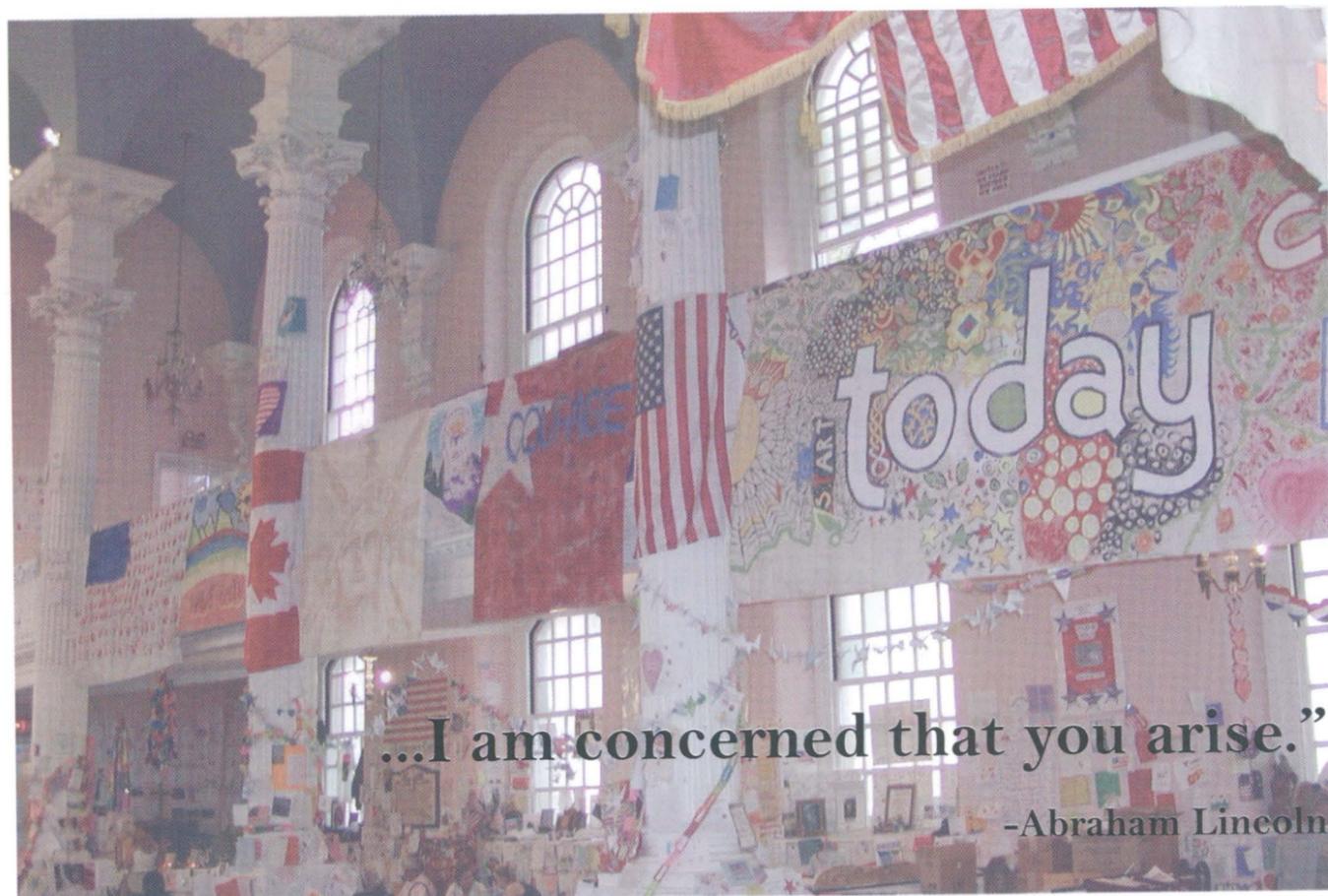
PTSD: Post-traumatic stress disorder



Our Mission

The Stony Brook WTC Wellness Program offers comprehensive, integrative healthcare of 9/11-related illnesses for WTC disaster responders. Integral to our mission of patient-centered care is an enduring support community, advocacy for our 9/11 responders, and cutting edge research efforts.

“I am not concerned that you have fallen...



...I am concerned that you arise.”

-Abraham Lincoln

Message from the Directors

When we started our work with the 9/11 responder community, we never dreamed our Center would expand as much as it has. We have grown from a small clinic providing limited health monitoring services for a few hundred World Trade Center (WTC) responders to a vibrant Center that monitors and treats many thousands. But the measure of our work is so much more than just the number of people we serve—it's about *how* we serve them, and our community, both locally and nationally.

Our patients' courageous work at the WTC sites resulted in lasting physical, psychological, and emotional effects that continue to change and develop over time. To be effective, those who provide care to 9/11 responders have had to evolve as well. For us, this has meant looking beyond disease management alone, and required creating a wellness community that empowers our responders to take part in their own continued wellness and healthcare. The concept of resilience is key to our work, and is reinforced through a diverse array of endeavors. In addition to increased clinical services and patient volume, we have built a robust research program and undertaken meaningful education and outreach efforts. We have strengthened our ties to the community and work with our patients in new and creative ways, all with the goal of improving their quality of life and our communities' understanding of the events and ongoing impact of the 9/11 disaster.

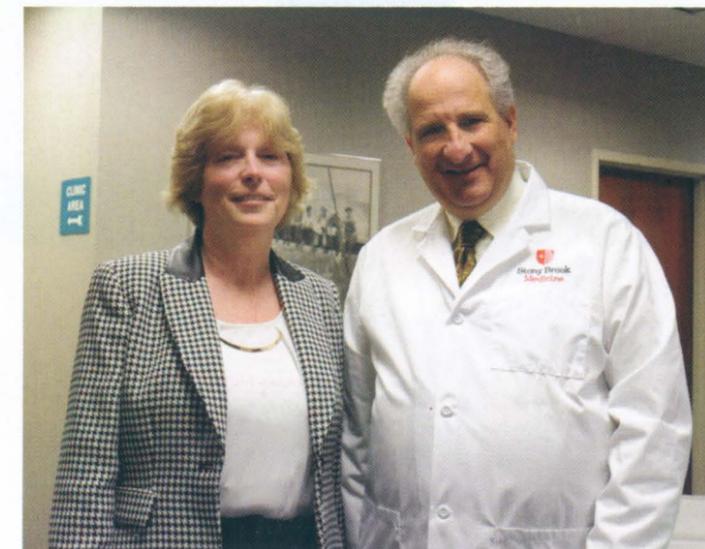
This evolution has led to our decision to rechristen our program as the Stony Brook WTC Wellness Program, emphasizing our lasting connection to the WTC disaster and the importance we place on promoting health, even in the face of chronic illness. Doing so gives us the opportunity to fully integrate our clinical work as the WTC Health Program Long Island Clinical Center of Excellence at Stony Brook Medicine with our research and education efforts. These interconnected tenets are essential to our work under this name.

As you'll see in pages that follow, all of our work is related. That is why our perspective on care encompasses so many things: we offer education so that the general public understands the ongoing effects of 9/11; we ensure our responders are empowered in their own care; we maintain a patient-centric Center with a focus upon comprehending and responding to patients' needs; and we run an innovative research program so that we can offer the most up-to-date and effective medical care possible. In short, we are here to serve our responders and the community at large.

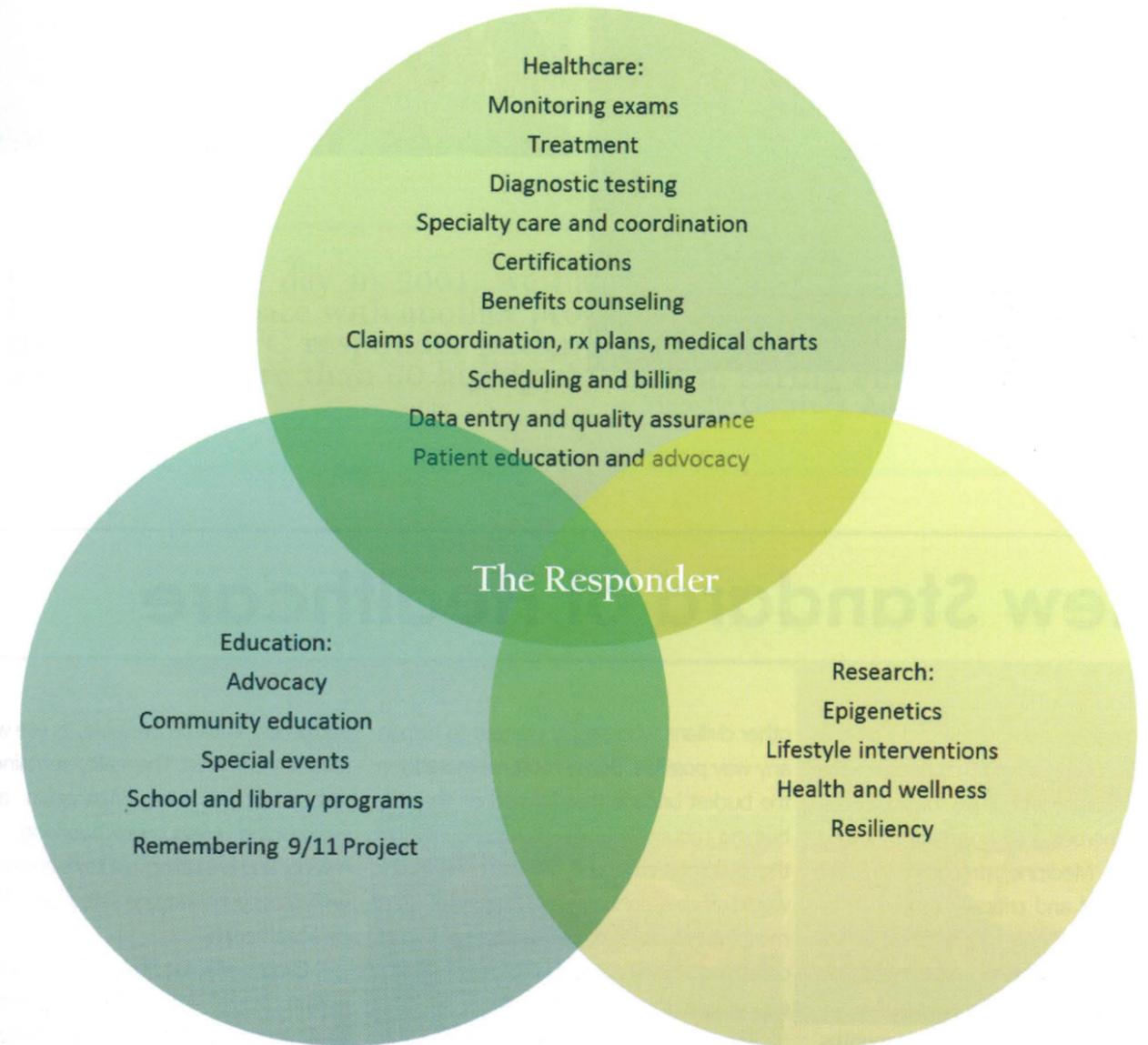
We are very proud of what we do, the people we serve, and the communities we work with. We are grateful to the men and women who permit us to care for them, and look forward to continuing this most meaningful work.

Thank you for your continued support.

Benjamin J. Luft, MD, Director and Principal Investigator
Melodie Guerrero, Administrative Director



**We are now proud to call ourselves the
Stony Brook WTC Wellness Program
which encompasses responder medical care in a
Clinical Center of Excellence, cutting edge
research, and increasingly vital education.**





A New Standard of Healthcare

On September 11, 2001, the attacks on the World Trade Center killed 2,977 people—the most devastating attack on US soil since Pearl Harbor. Numerous area hospitals, including Stony Brook Medicine, prepared to treat those wounded and critically injured. They stood at the ready, only to eventually realize no one was coming: city hospitals were able to handle the relatively few survivors.

In the following days, weeks, and months, more than 91,000 people responded to the WTC sites, coming to search for survivors, recover remains, and then participate in the massive cleanup effort. There existed a full spectrum of human experience: from fire rescue, law enforcement, and military, to iron and construction workers, demolition experts, mental health professionals, and

other civilians who simply wanted to help in any way possible. Some most memorably in the bucket brigade that formed on the still-burning mountain of debris just hours after the buildings collapsed, the recovery work would officially continue until May 2002 in the most inhospitable conditions: heat, threat of collapsing buildings, and an ever-present exposure to the poisonous cloud in the air.

This level of contact with a mixture of pulverized silica, asbestos, lead, fibrous glass, hydrochloric acid, pesticides, and much more was unprecedented.

In the first hours and days, the responders had little more than painters' masks, if that, and worked tirelessly in feet of ash and debris while more swirled in the air around them. Even as better safety

equipment became available, its use was not routinely enforced. The reality remained that responders in lower Manhattan and its surrounding areas were working, eating, resting, and breathing in a toxic environment with grossly inadequate safeguards for their personal health.

Even while medical and environmental experts could not predict the long-term health impact of the event and its aftermath, it was clear that there was an immediate need to offer healthcare to these dedicated individuals, thousands of whom were Long Islanders.

Stony Brook University Hospital (and other centers in Occupational Medicine) joined forces with labor unions, local politicians, New York City officials, the

federal government, the Red Cross, and others to secure the initial funds needed to establish a medical program that could measure the health impacts of 9/11 on the responders. Just months after 9/11, our center opened its doors to WTC responders, starting down a road that would lead to innovations in patient care and research and a new standard in post-disaster care.

We began by offering free medical screenings for local 9/11 responders as part of the WTC Medical Monitoring and Treatment

Program. Over many years of diligent work and advocacy, this health monitoring program grew into part of a complex monitoring and treatment program—now known as the WTC Health Program—a consortium of clinical centers supported by federal funding and administered by the National Institute for Occupational Safety and Health (NIOSH). As the program's Long Island Clinical Center of Excellence, we're humbled to serve more than 8,000 responders in Nassau and Suffolk counties.

Our model of care has continuously evolved since that first day in 2001. With each day that passes, we strive to provide compassionate and expert care, empower our patients in their own health (with a new focus on prevention and early detection), and give back to a community that has given so much to us, and for us.

On our opening day in 2001, we had but seven employees and shared limited office space with another program. **As of 2015, we track more than 8,000 WTC responder patients, manage two clinical locations, and employ more than 60 highly skilled and caring employees!**

—Melodie Guerrero, Administrative Director



Joining Forces

Soon after the first monitoring assessments were completed, it became clear that a specialized treatment program was needed for these 9/11 responders: something that would have to be built from the ground up. What seemed obvious to many—that 9/11 responders now needed quality healthcare—was not universally embraced. Finding funding and support has been critical at both the local and national levels, and is an ongoing battle. In 2004, NIOSH awarded a grant for our clinic to function as a Clinical Center of the WTC Medical Monitoring Program. In 2005, the American Red Cross issued another grant that would allow the Center to provide mental health services to responders. In 2009, the bill for the James C. Zadroga 9/11 Health and Compensation Act was formally introduced into Congress, and the rallying cries intensified—from grassroots organizers such as the Fealgood Foundation and 9/11 Health Watch; labor organizations including the Long Island Federation of Labor and the Nassau/Suffolk Building Council; George Bloom and John Durso; the late Bill Lindsay, David Parkinson, and Jack Kennedy; and politicians alike. The Zadroga Act was signed into law by President Barack Obama in 2011, providing for the first time direct federal funding for the WTC Health Program. Representatives from Congress, including Carolyn Maloney, Jerrold Nadler, Steve Israel, and Peter King, and Senators Hillary Clinton, Kirsten Gillibrand, and Charles Schumer have been instrumental in pushing forward this and other legislation and giving a voice to responders, especially as their health needs increase with each passing year.



THE FEALGOOD FOUNDATION

After being injured working on the pile, demolitions expert John Feal leapt back into action: this time, as a powerful and outspoken advocate for rescue and recovery workers. He founded the Fealgood Foundation, a not-for-profit organization whose primary mission is to assist responders who have been injured as a direct result of their work at the WTC sites. Their tireless work was crucial to the passing of the Zadroga Act in 2011, and continues to this day, from the individual level (connecting responders with doctors and helping find financial assistance) to the national level (working to spread awareness about 9/11-related health issues).

The Zadroga Act and the WTC Health Program

With the implementation of the James Zadroga 9/11 Health and Compensation Act in 2011, the national WTC Health Program was established. Administered by NIOSH and funded by the federal government and New York City, the program provides screenings, annual monitoring exams, and medical treatments for 9/11-related health conditions or conditions exacerbated by WTC exposure at no cost to patients. The Act also reopened the September 11th Victim Compensation Fund (originally closed in 2003), allowing those who got sick after 2003 to file for compensation. Funding for this program, which serves more than 70,000 responders and survivors in all 50 states (as of 2015), through five clinical centers of excellence and a nationwide provider network (NPN), is up for renewal in 2016.



Congressman Peter King at a press conference about compensation for 9/11 responders and victims in 2014. (Petr Svab/Epoch Times)



Senator Kirsten Gillibrand, joined by Congresswoman Carolyn Maloney and others, argues for passage of the Zadroga Act in 2010. (CNN)



Glen Klein with John Feal at a press address for the Fealgood Foundation.

AS OF FEBRUARY 2015, 71,186 PEOPLE WERE ENROLLED IN THE WTC HEALTH PROGRAM. OF THOSE, 33,557 PEOPLE HAD AT LEAST ONE CERTIFIED CONDITION UNDER THE PROGRAM.

(CDC 2015)

Healthcare

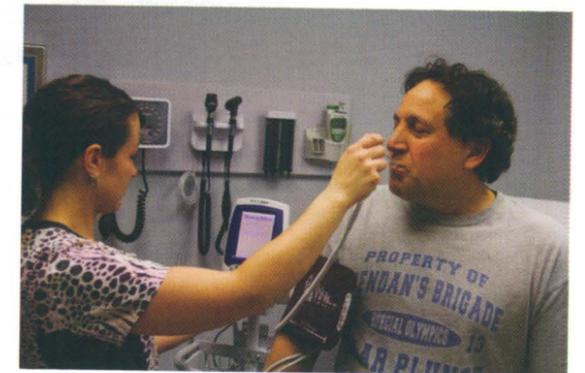
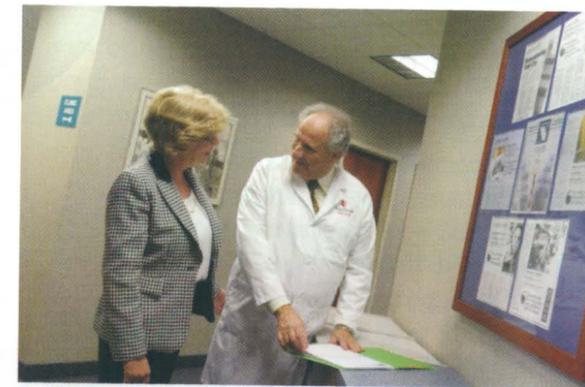
- Monitoring exams
- Treatment
- Diagnostic testing
- Specialty care and coordination
- Certifications
- Benefits counseling
- Claims coordination, rx plans, medical charts
- Scheduling and billing
- Data entry and quality assurance
- Patient education and advocacy

A Unique Philosophy

From the beginning, we've offered our patients much more than standard outpatient clinic services as the Long Island Clinical Center of Excellence of the WTC Health Program. The importance we place on patient retention is built around the idea that people who feel invested in their healthcare will participate in and prioritize it.

Grounded in Dr. Luft's vision for a vibrant and integrative patient-centered program, our clinical center is exceptional in its care for 9/11 responders. Our approach integrates personalized preventive care and treatment, social work and psychiatry, and other specialties as part of our distinctive paradigm.

Because of the nature of how 9/11-related illnesses are manifesting (many not for years after initial exposure) we are continuously assessing and evolving our medical care model. Many of the disease trajectories and treatment response patterns are atypical; thus, the medicine we practice is highly specialized, requiring a vibrant research program that drives innovative approaches to care.



A Patient-Centered Approach

Medical Monitoring

One of the main components of our program is to provide each patient an extensive annual medical exam (the Monitoring Exam). Fundamental to our epidemiological approach, this exam is designed to document the totality of the impact of 9/11 exposures on health outcomes over time. The information gathered from this exam also, crucially, allows our research team to identify changes in health and disease onset—permitting us to monitor the course of illness and adapt our plan of care, both for individuals and our members as a population. Monitoring is crucial to anticipating what kind of care is needed: when data from the various clinical centers pointed to the likelihood of cancer onset in responders, the Program began offering colon and breast cancer screenings to our patients.

Our clinicians play an important role in documenting 9/11-related conditions. Before a health condition can be certified by the WTC Health Program, a program clinician must make a determination based on a careful examination (during the annual monitoring visit) of both the onset and course of symptoms relative to the patient's specific 9/11 exposure history and the type of health condition developed (the diagnosis). If the Program certifies the condition, then patients are approved to begin receiving treatment through our Center.

Treatment for 9/11-Related Conditions

Our LI-CCE provides treatment for conditions on the List of WTC-Related Health Conditions (this information is updated on a rolling basis; the most current information can be found on the CDC website). Patients in our treatment program not only benefit from the expertise of the Center's clinical staff, but have access to specialists, diagnostics, inpatient care, and medication for their certified conditions. Treatment appointments vary and include (but are not limited to), sick visits, prescription renewals, review of test results, and referrals to specialists.

Our network of providers includes experts specializing in occupational medicine, otorhinolaryngology, pulmonology, psychiatry, and gastroenterology. Our expanded specialty network also includes the best oncology care providers on Long Island and in the New York metropolitan area.

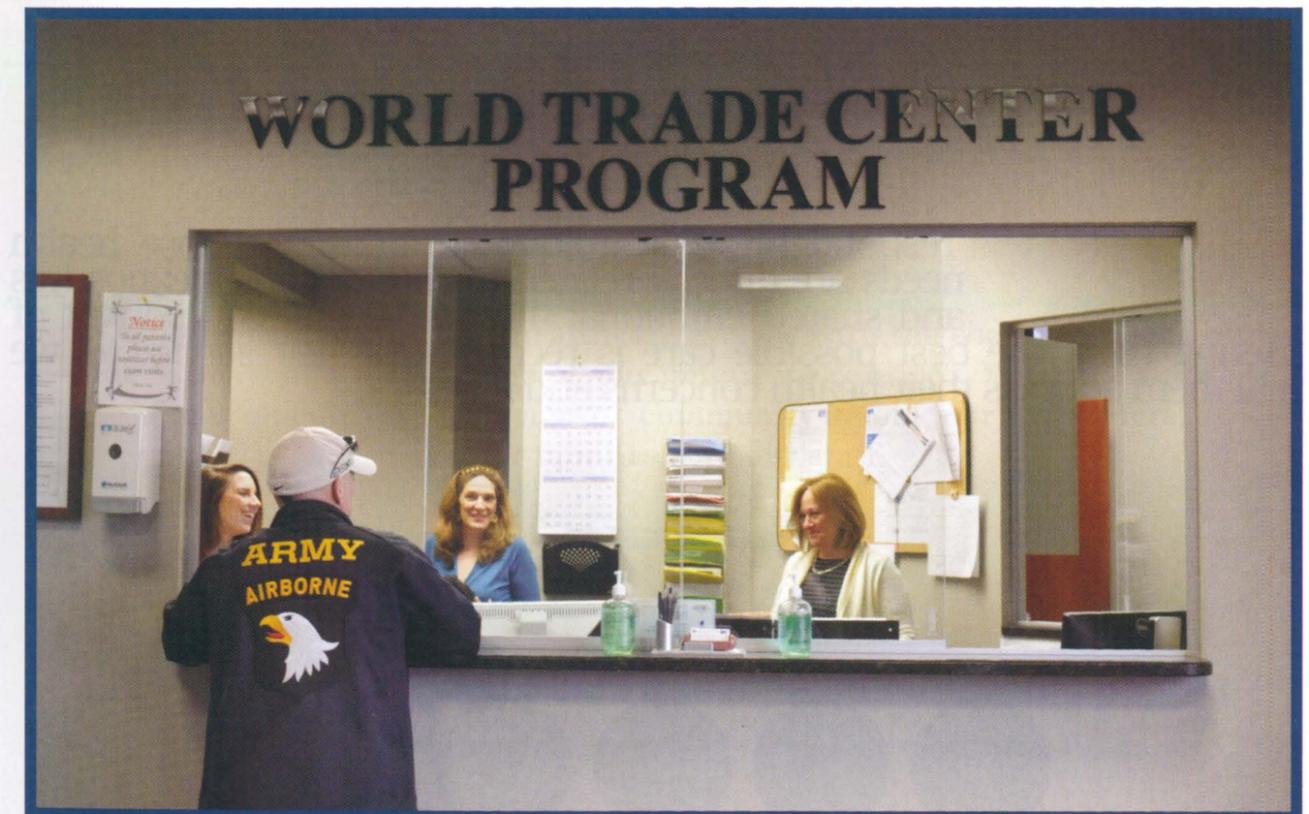


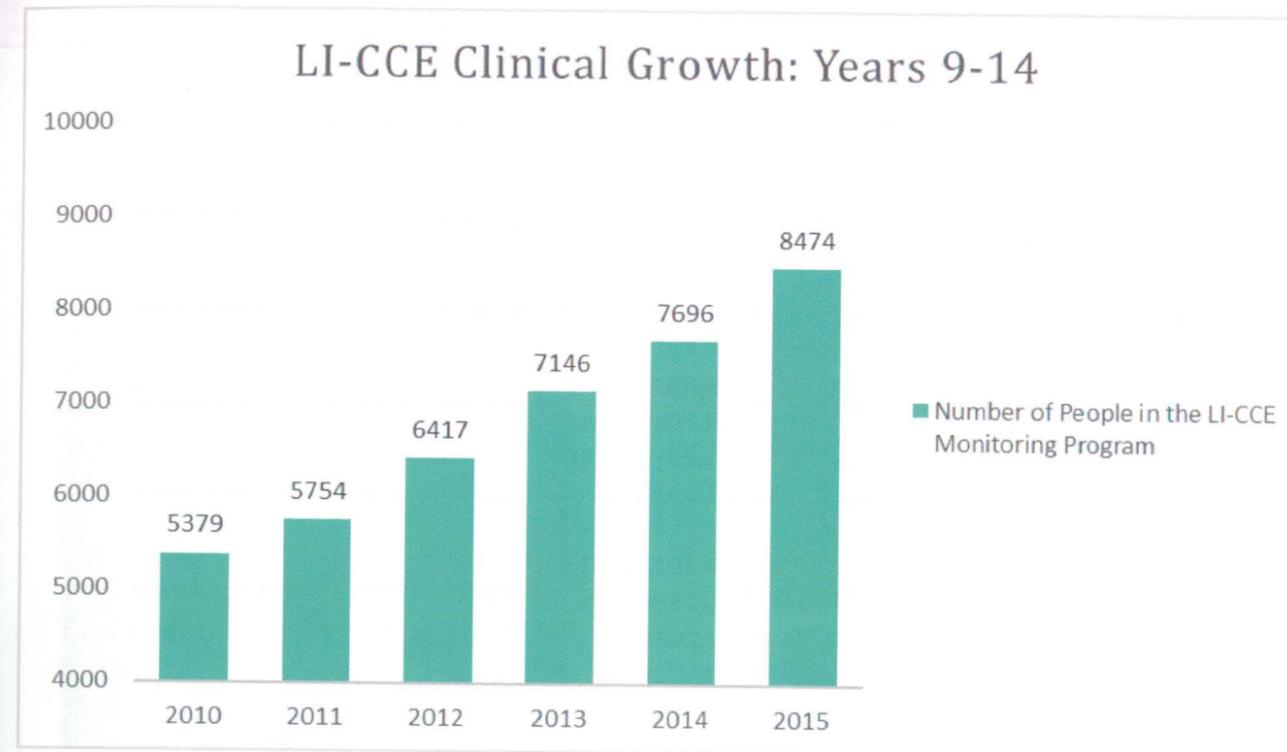
Care Management and Advocacy

It's essential to our mission that our patients have a seamless healthcare experience. In addition to the medical care we offer, we provide supportive services to help our patients understand and utilize their Program benefits. One of the many ways in which our program is unique is that it often requires extensive documentation; navigating this can be confusing for our patients and so we have implemented numerous resources to minimize this stress. Our nurses and social workers consult individually with each patient to coordinate their care, offering additional support for our patients with cancer. We educate, counsel, and connect patients to outside resources (including public benefits like the Victim Compensation Fund and workers compensation) that can help them cope with the social and economic repercussions resulting from their 9/11-related injuries and illnesses.

Our claims department reviews and processes between 2,000 and 4,000 claims each month for monitoring, treatment, and medications, in addition to processing claims from specialists and other external providers (to whom we refer our patients for care). These functions are essential to making sure that our patients are covered for services ranging from bloodwork to emergency room visits and inpatient care. Another crucial focus of our claims specialists is to expand the WTC Health Program Healthcare Network for cancer care, with the goal of making it easier for patients to see providers of their choice. The work doesn't stop there: our staff also ensures that these providers are well-versed on WTC Program guidelines so that our members receive informed, specialized care even when they step outside our clinic doors.

An important position unique to our Center is that of the Patient Advocate. Every responder who belongs to our program has a point person, whom they can call with questions, concerns, or updates. These individuals do exactly as their title suggests: they serve the patient's interests and keep them informed not only about pertinent medical information, but programs and services on offer. We like to think of our advocates as the patients' ultimate resource.





9/11 responders are a unique community whose health needs are directly related to their complex exposures and shared emotional trauma. A vital component of offering them the best possible care is recognizing their service as we help them address their health concerns and illnesses.

Our exceptional model of healthcare evolves with the changing needs of our patients and the findings of our innovative research. We place a major focus on cultivating a sense of community among our responders, their families, and our staff.



Our Health Community

Our community care model informs the work of every staff member at our Center. While our patients interact with our doctors, nurses and nurse practitioners, social workers, and their dedicated patient advocates, behind the scenes our clinical location thrums with activity. A multitude of staff are responsible for ensuring our efficiency and quality: they schedule appointments; facilitate pharmacy orders and authorizations for procedures; approve and process claims; manage clinical research data; coordinate and expand our provider network; and more. This is just the tip of the Stony Brook WTC Wellness / LI-CCE iceberg.

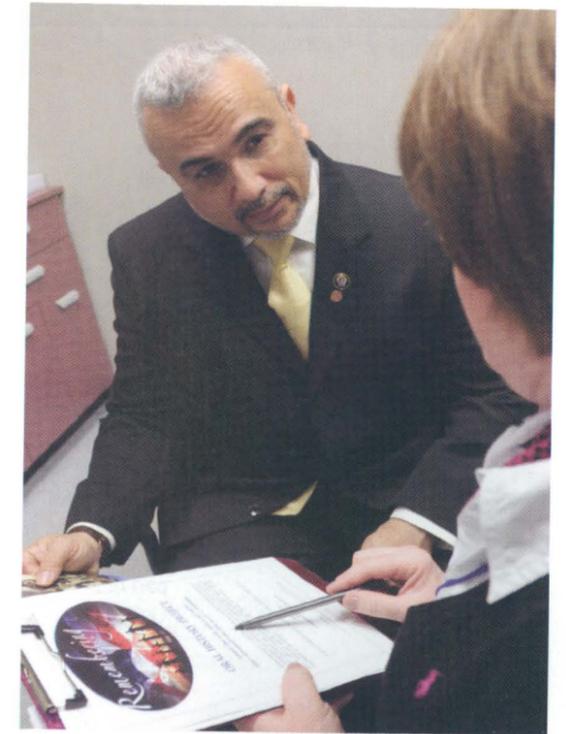
Our member patients not only return for medical monitoring year after year, but they attend our events, recommend our services, participate in our studies, and join in our preservation efforts. With each passing year, the evidence of our success is found in the thousands of 9/11 responders who consider us an extension of their family. It is incredibly meaningful to know that despite the tragic legacy of 9/11, we can provide a place of health and healing.



Responders proudly take part in the ribbon cutting ceremony marking the opening of our state-of-the-art clinical space in 2009.



Pharmacy specialist Toni Cerruto helping a patient on the phone.



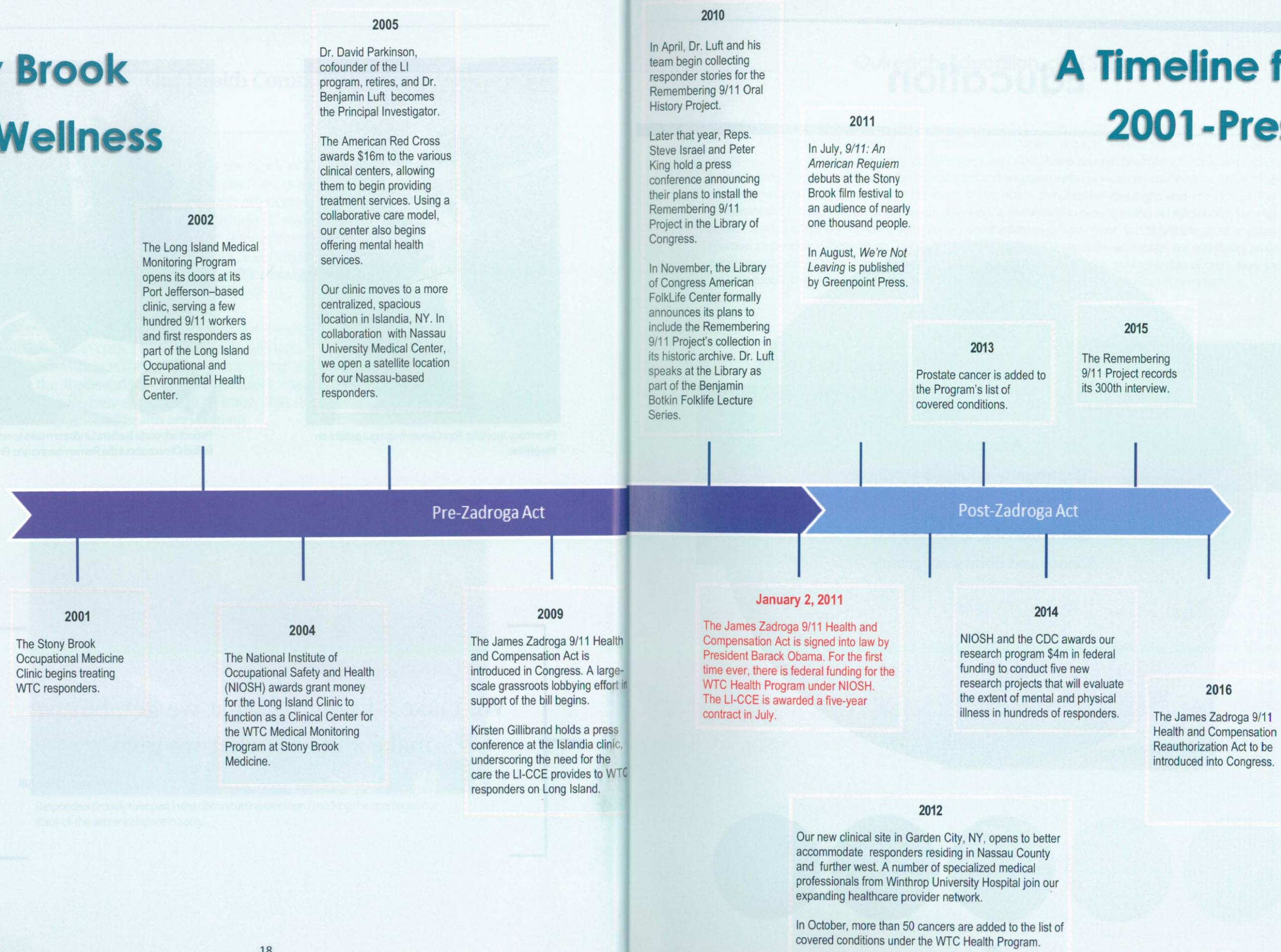
Patient advocate Barbara Lindstrom talks to responder Rafael Orozco about the Remembering 9/11 Project.

We make a living by what we get, but we
make a life by what we give.

—Winston Churchill

Stony Brook WTC Wellness

A Timeline from 2001 - Present



2002
The Long Island Medical Monitoring Program opens its doors at its Port Jefferson-based clinic, serving a few hundred 9/11 workers and first responders as part of the Long Island Occupational and Environmental Health Center.

2005
Dr. David Parkinson, cofounder of the LI program, retires, and Dr. Benjamin Luft becomes the Principal Investigator.

The American Red Cross awards \$16m to the various clinical centers, allowing them to begin providing treatment services. Using a collaborative care model, our center also begins offering mental health services.

Our clinic moves to a more centralized, spacious location in Islandia, NY. In collaboration with Nassau University Medical Center, we open a satellite location for our Nassau-based responders.

2001
The Stony Brook Occupational Medicine Clinic begins treating WTC responders.

2004
The National Institute of Occupational Safety and Health (NIOSH) awards grant money for the Long Island Clinic to function as a Clinical Center for the WTC Medical Monitoring Program at Stony Brook Medicine.

2009
The James Zadroga 9/11 Health and Compensation Act is introduced in Congress. A large-scale grassroots lobbying effort in support of the bill begins.

Kirsten Gillibrand holds a press conference at the Islandia clinic, underscoring the need for the care the LI-CCE provides to WTC responders on Long Island.

2010
In April, Dr. Luft and his team begin collecting responder stories for the Remembering 9/11 Oral History Project.

Later that year, Reps. Steve Israel and Peter King hold a press conference announcing their plans to install the Remembering 9/11 Project in the Library of Congress.

In November, the Library of Congress American Folklife Center formally announces its plans to include the Remembering 9/11 Project's collection in its historic archive. Dr. Luft speaks at the Library as part of the Benjamin Botkin Folklife Lecture Series.

2011
In July, *9/11: An American Requiem* debuts at the Stony Brook film festival to an audience of nearly one thousand people.

In August, *We're Not Leaving* is published by Greenpoint Press.

January 2, 2011
The James Zadroga 9/11 Health and Compensation Act is signed into law by President Barack Obama. For the first time ever, there is federal funding for the WTC Health Program under NIOSH. The LI-CCE is awarded a five-year contract in July.

2013
Prostate cancer is added to the Program's list of covered conditions.

2012
Our new clinical site in Garden City, NY, opens to better accommodate responders residing in Nassau County and further west. A number of specialized medical professionals from Winthrop University Hospital join our expanding healthcare provider network.

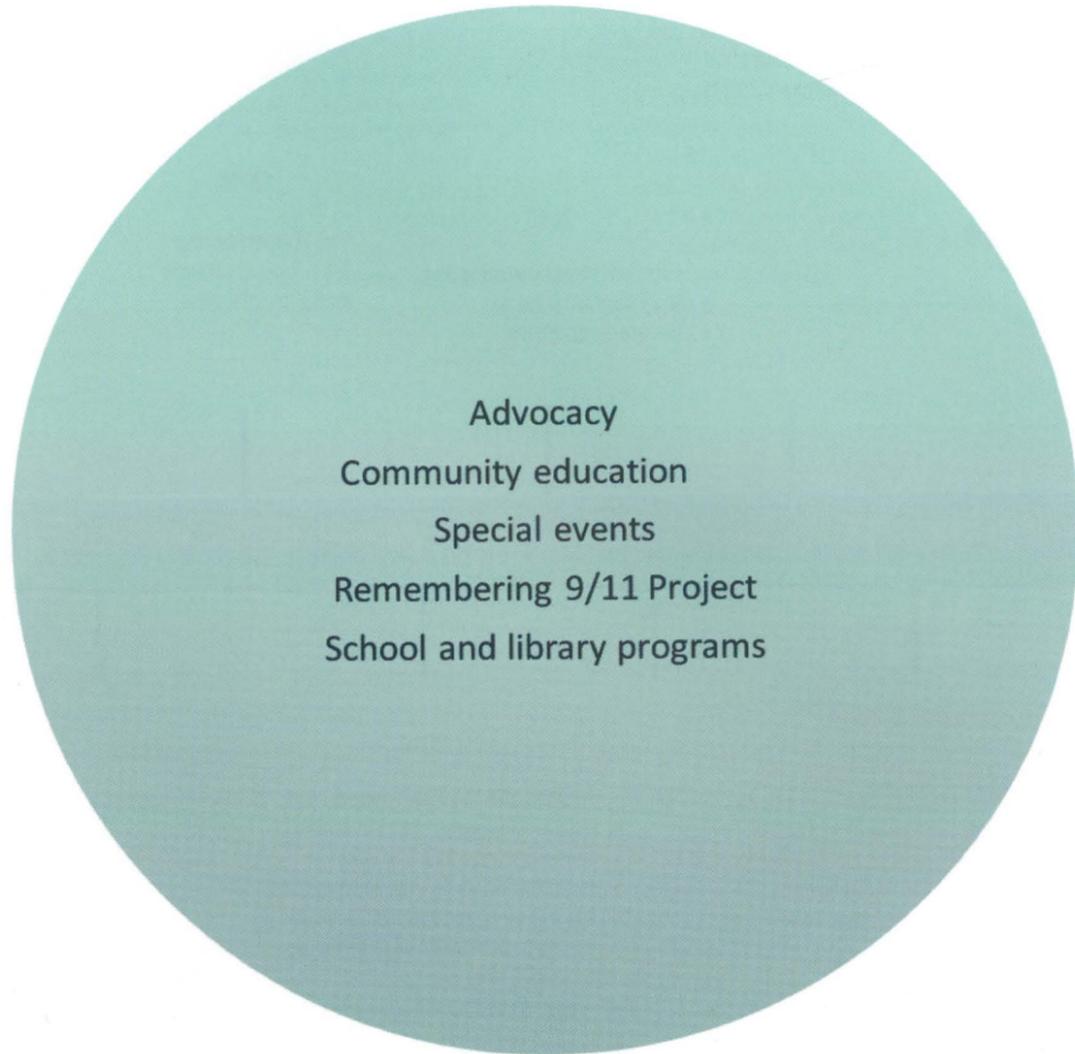
In October, more than 50 cancers are added to the list of covered conditions under the WTC Health Program.

2015
The Remembering 9/11 Project records its 300th interview.

2014
NIOSH and the CDC awards our research program \$4m in federal funding to conduct five new research projects that will evaluate the extent of mental and physical illness in hundreds of responders.

2016
The James Zadroga 9/11 Health and Compensation Reauthorization Act to be introduced into Congress.

Education



Outreach, Education, and Support

We put a premium on fostering and sustaining the legacy of 9/11 responders. Not only do we consider nurturing a sense of community among our patients and staff requisite to care, but we also believe it's our responsibility to make sure other responders know covered healthcare is available to them and how to access it. By providing educational resources and engaging with our local communities, we strive to give all people, whether directly connected to the event or not, access to education about 9/11 and its consequences and encourage their investment in our endeavors. This work is manifested in programming at high schools, libraries, and public events, and by working closely with 9/11 responder advocacy groups. We're also passionate about engaging our member responders in these efforts, inviting them to speak about their experiences through our oral history project, at public events, and in other ways. We've found that personal empowerment and ownership of one's story can be valuable tools in the healing process, and we strive to create and support such opportunities at every turn.



Putting Down Roots in the Responder Community

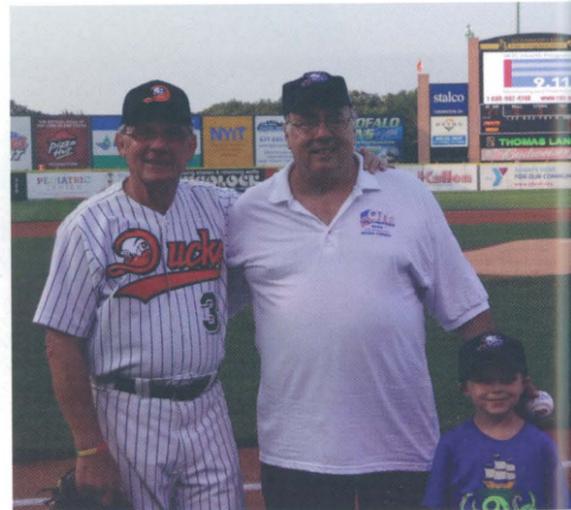
From the day we first opened our doors to help WTC responders, our clinicians and administrators understood that this work would be different from any they had done in their careers thus far. For many of the staff, the phrase “comprehensive care” has taken on a deepened and more meaningful definition, as they not only help patients navigate their care, but work to foster feelings of trust and togetherness. Going out into the community at large is an equally important piece of our work—we continually strive to educate the general public about our program and the effects of 9/11, as well as ensuring that potentially eligible individuals know about the range of services available to them. Endeavors like the Remembering 9/11 Oral History Project and our library and school initiatives are important components of this work.

Helping develop a supportive and empowering community that extends beyond our clinic doors is at the heart of our mission.

Giving our responders a voice is a responsibility we take seriously. Working with organizations like the Fealgood Foundation, the New York Committee for Occupational Safety and Health (NYCOSH), LI Federation of Labor, WTC Health Registry, the Johnny Mac Foundation, Laughter Saves Lives, and others, we are dedicated to sustaining and improving grassroots education, advocacy, and support about 9/11 and the ongoing needs of responders. This is in addition to the community events we are proud to offer our members and their families.



Julie Broihier speaks at a VCF informational session.



Having fun at the LI Ducks 9/11 Responders Night.



Melodie Guerrero speaking at the Fealgood Foundation Gala.



Teaming up with Laughter Saves Lives at the Suffolk Theater to benefit 9/11 responders and their families.



9/11 Responders Remembered Park annual ceremony.

“Sometimes it’s easy for first responders to feel alone as time passes, but we don’t ever feel forgotten by the staff [here].”

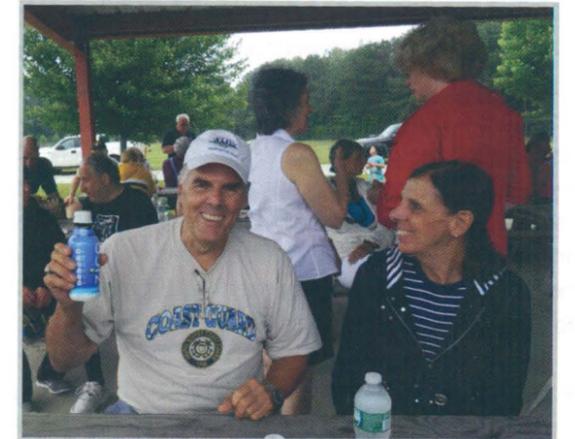
—William

“The programs that have grown from this clinic are extraordinary. . . . As a patient [and] responder, my life has been touched positively by the professionalism and untiring efforts of the Long Island Clinic.”

—Anthony

Annual WTC Responder Family Fun Day and Picnic

In partnership with the Fealgood Foundation and with the generous support of many local businesses, we are delighted to host an annual outing for our responders and their loved ones. This event, which typically draws several hundred attendees and depends upon Center staff volunteering their time, truly highlights the strength of the bonds we have fostered with our patients and the local community. From face painting for the kids to raffles and chili cook-offs under the sun, this event is a special way for the Center to say thanks to our responders. Our staff members, including Senior Member Advocate Sonia Fore and Outreach and Education Specialist Patrick Flynn, collaborate with the Fealgood Foundation and event donors for months in advance to plan a day that will demonstrate our gratitude for all our responders do.



With gratitude to the local sponsors whose generosity has made these events possible in years past

Adam Small & Long Island Party
Xpress
BAB Radiology
The Buggy Jones Band
Carlo's Bakery of Hoboken
Costco
CWA 1104, President George Bloom
Deer Park Fire Department
Deer Park Water

FealGood Foundation
Fusco, Brandenstein & Rada, PC
Glenn Wayne Bakery of Bohemia
Herr Foods
Hint Water
IBT Local 282
IUOE Local 138
Impala Press
Nick Kester
Restaurant Depot

Ricardo Rivera
Sam's Club
Star Dust Band
Syosset Massage School
Texas Roadhouse of Deer Park
Town of Babylon
Town of Islip
Tuesday's Children
Wonder Bread
Zico Water

Remembering 9/11 Project

The Remembering 9/11 Oral History Project is an endeavor with deep roots. While treating responders at the Stony Brook WTC Wellness Program / Long Island Clinical Center of Excellence at Stony Brook University in the years after September 11th, director Dr. Benjamin Luft and his colleagues began to feel profoundly that it was their responsibility not only to offer medical care, but to act as stewards for their patients' unique memories of that day and their work at the WTC sites. Coverage for their 9/11 healthcare was the hard-won result of much advocacy and work by responders and supporters; during their clinic visits, countless responders worried aloud that the benefits would disappear as the years passed. And so, as a way to preserve history recorded from a personal perspective and keep the conversation about 9/11 alive, the project was founded in 2009. A volunteer effort, it began with five willing responders; a handful of faculty, staff, and students from Stony Brook and Hofstra University; a video camera; and scant other resources.

The project is now the crowning achievement of our Program's outreach and education efforts, with an archive of hundreds of interviews. This rich collection captures the stories of responders, responders' family members, and others who participated in the World Trade Center disaster response. Thanks to the dedication of the program staff that work on the project, the support of those who believe in the importance of this endeavor, and the generosity of those who share these deeply personal stories, the collection continues to grow.

Ultimately, Remembering 9/11 will serve as the largest collection of eyewitness testimony of the 9/11 disaster response effort and its impact on the people involved. A valued goal of the Project is to provide a foundation for thoughtful discussion of our response to and recovery from the WTC attacks, from the very personal level to a very public one. By ensuring that history does not only record a macro perspective of this event, we hope to give voice to conversation about the human consequences of disaster work, the politics of disaster response, the fragility of human life, the strength of human character, and the power of community to withstand tragedy.



Remembering 9/11 inspired Congressmen Steve Israel and Peter King to announce legislation that would build on the project, coordinating a national collection of video and audio recordings of testimonials of emergency responders and recovery and cleanup workers who responded to the September 11, 2001, terrorist attacks.

Purpose

This project is a natural outgrowth of years of treating WTC responders in a clinical setting. While Dr. Luft and his colleagues meticulously recorded health statistics, research results, and notes in medical records, they soon realized that these functional documents left no room for an equally important part of the responder's story—their recollections of the 9/11 disaster and their involvement with the rescue and recovery efforts. Rather than risk losing these personal histories to time, Remembering 9/11 was started.

Not only does it give responders and others a much-needed voice, but it has created the opportunity for our local and national communities to better understand the continuing impact of this disaster and its unprecedented effects on the involved responders and their families. By preserving these accounts and making them publically accessible, we are giving future generations the chance to understand not only the larger historical impact of 9/11, but the many ways in which it has irreparably affected the lives, health, and legacies of thousands of people.

Preservation

Each oral history is recorded on digital video and audio and professionally transcribed. These transcriptions are then edited, with the work focusing all the while on preserving the power of the responder's voice and storytelling style. These various media formats have allowed the Project to pursue related efforts, utilizing the collection to the fullest extent.

Accompanying the oral histories is a veritable treasure trove of photographs and other materials donated by participants. The Project will donate the collection in its entirety to the American Folklife Center at the Library of Congress in Washington, DC, where it will remain available to the public and be housed into perpetuity. The public will be able to search the archive by information provided by the responders (e.g. name, hometown), occupations, and extensive metadata collected by the project staff. We are continuously working to expand the reach of this project, creating partnerships with various other organizations and founding additional ventures.

Project Extensions

Remembering 9/11 has allowed for the establishment of other creative endeavors, including the documentary, *9/11: An American Requiem*, and a companion book, *We're Not Leaving*. They were produced in 2011 for the tenth anniversary of September 11th, and now serve as the basis for our educational and outreach programming.

From the Remembering 9/11 Archives

*Roberta, downtown NYC resident and
Seaman's Church Institute volunteer*

The thing that stands out to me most of all was how humble these guys were. They were risking their lives and they had to know they were risking them. . . . **Somehow it felt never like enough.** Because it never was enough. It made me feel really humbled, because these guys were doing something really so important, and they were the ones who were grateful. They were extraordinary people.

Danny, NYPD detective

The streets were full of people. We found ourselves near Ground Zero and joined the bucket brigade . . . We felt we had to do something. There were so many different agencies, so many different people, whether it was EMTs, fire department guys, civilians. **When they say heroes – there's a lot of people involved. It's all kinds of people.**

*John, security manager and
retired NYPD officer*

When the opportunity arose to do this oral history, even though I had some trepidation about it, **I thought it might be a good idea for me, to kind of put it in perspective,** and maybe sort it out a little bit better than I had been, in a safe setting.

Jennifer, attorney and widow of FDNY firefighter

I go to every wake that I can go to, just to hold the hand of another widow because I had that, and I know that's important. **I just think it's important for those widows to know they're not alone. There's a lot of us out there.** A lot of widows, a lot of young, very young children. It's important to support other people.

Ken, volunteer firefighter

They call it 9/11 lung syndrome. That's what the government calls it. They don't know what it is. It's not emphysema. But they can't tell me what it is. **If it wasn't for this—the 9/11 health program—I don't know where I'd be right now.** I might be dead ... whatever. I tell everybody to come here.

Our Book

We're Not Leaving



We're Not Leaving is a compilation of powerful first-person narratives told from the vantage point of World Trade Center disaster workers—police officers, firefighters, construction workers, and other volunteers at the site. From Tyree, a court officer who is trapped in the Tower 2 basement while rescuing a critically injured woman, to Michael, an NYPD detective who spent several months at the disaster site, became disabled from WTC-related illness, and began a foundation to support the families of sick police officers, the book tells the deeply personal stories of thirty-six 9/11 responders, revealing how ordinary people responded to disaster and devastation in extraordinary ways. *We're Not Leaving* spans that harrowing day; the subsequent rescue and recovery efforts; and the ongoing social, physical, and psychological effects on responders. At the heart of every story is evidence of the kinds of personal strength and resilience that testify to the power of the human spirit.

“I think I did my best. I had a chance to leave and I chose to stay. I wish more people could’ve been saved. I definitely have survivor’s guilt...my body hurts all the time, every day. I try not to give in to that; I just get up and I try to live my life every day to its fullest.”

—Carol, NYPD officer

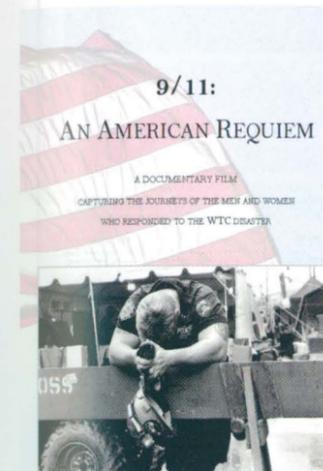
We're Not Leaving was covered by the *New York Times*, Huffington Post, Blogcritics.org, the *Washington Post*, *Bookpage*, and other media outlets. The book, published by small and independent publisher Greenpoint Press, is available in paperback and ebook formats at booksellers including Barnes & Noble, Amazon, Powell’s, and Indiebound, and in places like the 9/11 Memorial and Museum store and the FDNY Museum shop. It is our mission to ensure its availability to the reading public, particularly as its subject matter is one of lasting importance.



Dr. Luft and former Emergency Services Unit officer William Fischer speaking with the *Daily News*. (Stephen Barcelo/*Daily News*)

Our Film

9/11: An American Requiem



“The strength of this country is its people and its compassion.”
—from the film

9/11: An American Requiem is the poignant, inspiring story of the journeys of many World Trade Center responders, from their memories of the hellish scene of the disaster on 9/11 to their renewal ten years later. This unique documentary offers a singular, candid glimpse into the profound long-term effects of 9/11 via the voices of the responders. Although these intimate, unfiltered accounts often relate sorrow and pain, they also celebrate our ability to transcend unimaginable hardships and still maintain our humanity.

The documentary debuted to a crowd of a thousand people at the Stony Brook film festival at Staller Center for the Arts. It has been shown at numerous public events and has also been featured on CBS’s *60 Minutes*, PBS, News 12, and in several national and regional media outlets, including the *NY Daily News*, *Newsday*, and others.



Scott Pelley talks with Dr. Benjamin Luft.



Responder John Feal at the premiere of the documentary.



Responders are interviewed by Scott Pelley for *60 Minutes*.

Library and School Programming

The Responders Remember Library Partnership

The Responders Remember library partnership program is a coordinated effort between our Center and local Long Island libraries. Serving more than 8,000 responders in the area, our program sees firsthand the ongoing ramifications of 9/11 and the subsequent rescue and recovery efforts. We're committed to providing this programming as an educational resource and forum for the public to learn about the unique and personal experiences of WTC responders—from NYPD and FDNY to construction workers, iron workers, and volunteer firefighters, so many of whom were from our own communities.

We are thrilled to partner with area libraries to adapt programming that suits their needs. Available features include:

- A representative from the WTC Program to introduce the event and answer questions
- Video vignettes of interviews with WTC responders from our ongoing oral history project and documentary, *9/11: An American Requiem*
- Access to *We're Not Leaving*, a powerful collection of 36 first-person responder narratives
- Q&A with a responder

Responders Remember is an excellent, interactive source of information for the general public and students who are interested in understanding how ordinary people from all walks of life (not just law enforcement and rescue) respond to tragedies like 9/11. Like the media we've produced through the Remembering 9/11 Oral History Project, our library partnerships thrive on the candid, evocative, and inspiring nature of the stories being told. We've had the pleasure of working with many local librarians to create special events, both around the anniversary of 9/11 and at other times during the year.

REMEMBERING 9/11:
An Oral History of Responders to the WTC Attack

FILM AND DISCUSSION
MEET A 9/11 HERO
WEDNESDAY, SEPTEMBER 21ST
7 P.M.

When and remember the 9/11 attack on the World Trade Center. This special program will feature the screening of "Remembering 9/11: An Oral History of Responders to the WTC Attack," followed by a panel discussion with one of the featured responders in the film. The panel will give a firsthand account of the events as experienced that day and speak about the impact it has had on his life.

The healthy program provides a powerful communication example of professional generosity, selflessness, and bravery. The Remembering 9/11 project is the brainchild of Dr. Benjamin Luft, Director of the Long Island World Trade Center Program (the World Trade Center Health Program) at Stony Brook University.

Cooper of the compilation book, "We're Not Leaving" 9/11 Responders Tell Their Stories of Courage, Hardship, and Survival, will be available for sale. All proceeds benefit 9/11 Responders through the World Trade Center Health Program. For more information about the project, visit www.911respondersremember.org.

Cold Spring Harbor Library & Environmental Center
400 Main Street, Cold Spring Harbor, NY 11724
631-462-6000 www.cshlibrary.org

MEET A 9/11 FIRST RESPONDER
Tuesday, September 17 at 1:00 PM

The Long Island World Trade Center Health Program at Stony Brook will be presenting a few video vignettes from their archive of 9/11 responder stories collected for the World Trade Center Oral History Project, "Remembering 9/11."

Following the video presentation will be a Q&A session with a local World Trade Center responder who will be able to open up to the audience members about their personal experiences at the WTC site after the September 11, 2001 WTC attacks. Through their stories you will see how these responders persevered when faced with horror and confusion and regained their humanity through community, commitment and hope. No registration is required.

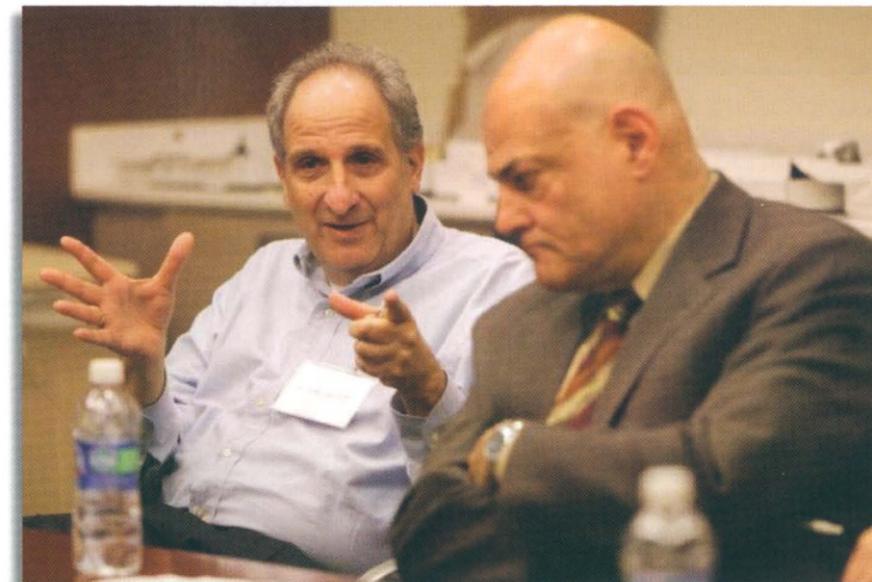
Stony Brook University
100 Nicolls Avenue
Stony Brook, NY 11790
www.stonybrook.edu

Remembering 9/11: Meet the Hero

John Feal founded the Feal Good Foundation after he lost half his foot while searching for survivors and excavating debris at Ground Zero. This program will feature selected interviews from the documentary film *9/11: An American Requiem*.

Tuesday, September 13, 2011
7:00 - 8:30 p.m.

CONNETQUOT PUBLIC LIBRARY
Expand your mind. Enrich your world.



Dr. Luft and attorney Vic Fusco talking with students. (Jessica Rotkiewicz/Newsday)

9/11: Anatomy of a Healthcare Disaster

This medical school-level elective course was created by Dr. Benjamin Luft at Stony Brook University School of Medicine through the Medicine in Contemporary Society (MCS) subprogram, which is part of a larger effort to integrate the social sciences and humanities into the medical school curriculum. Using a multidimensional approach, this class helps future clinicians understand the development and treatment of various physical and emotional health conditions caused by exposure at the WTC site through the lens of narrative medicine. Indeed, it was in the pilot semester that Dr. Luft and colleagues began work on creating the Remembering 9/11 Oral History Project.

Drawing on decades of clinical expertise and specialized treatment of 9/11 responders, Dr. Luft has crafted a core syllabus that addresses the following critical topics:

- How the WTC post-disaster environment contributed to physical and emotional health risks for responders
- How students should incorporate various factors into evaluations of WTC-related illness—and how these issues impact the responders and the course of their illnesses
- Why a narrative medicine approach is essential for understanding the complexity of WTC-related illnesses

While examining these issues from the perspectives of patient, physician, and even affected family members, the course has also been adapted to address concerns newly identified as time progresses. Multimedia resources include first-person narrative videos that address the range of WTC disaster effects—from the micro: personal health and spirituality impacts, to the macro: legal and sociopolitical consequences. Each semester, Dr. Luft is proud to host guest speakers, ranging from responders to medical and legal experts to journalists. Author and physician Dr. Qanta Ahmed has presented a number of times, on topics ranging from technology and medicine to the idea of physician as witness. In the past, the course even adopted a webinar and social media component, where both seminar students and others could post comments, questions, and reflections using tools like Facebook and Twitter. Tech journalist Sree Sreenivasan joined Dr. Luft to discuss the role of social media in a physician's work, with particular attention to communicating with patients.

Explorative, analytical, and engaging, *An Anatomy of a Healthcare Disaster* is essential in a world where practicing clinicians will need to address toxic and traumatic disasters.

Dear Carol, Glen and Roy,

9/30/14

Thank you so much for visiting us yesterday. I feel truly blessed that there are people like you protecting us and our country. Your actions were beyond heroic and I am in awe of your strength and power. I will fight for the ~~George~~ Zadroga bill and for the rights that you deserve. Thank you for your service to our country.

Wishing you happiness and joy,
Lana

Ward Melville High School

Dear Arthur, Anthony, and Phillip,

Thank you for coming to our school and speaking to us about your experiences on September 11th. I learned a lot more about that day than I knew before and it was interesting to hear about what happened from people that were actually there. All the stories that you told really made me understand just how everyone was feeling when the attacks happened.

I was very young when the attacks happened and I don't remember anything about it, so hearing everything that you said and learning about it in school really helped me to know what exactly happened. The terrorists may think that they weakened us as a nation, but truthfully they made us stronger and brought us closer together.

All three of you are heroes in your own right. Without your help who knows what everyone would've been like on that day. There probably would have been many more people dead and many more that were suffering. Even if you don't think you are heroes, all of the people that you helped out definitely do. They won't ever forget that day and the sacrifices you made to save their lives.

You are very inspiring men and are great role models for young children who want to save lives when they grow up. Thank you for helping out on that tragic day and every other day. There should be more people like you in the world. It would definitely be a better place.

From,
Daniella

Dear Carol, Glen, and Roy,

Thank you for coming to visit us on your free time and sharing your experiences with us. All of your stories were very interesting and some even sounded familiar to myself on a personal level. My father was also a first responder who had left from home to go and help but he doesn't talk much about that day and the months that followed for obvious reasons. Again, thank you for coming and sharing your insight with all of us.

Sincerely, Aeon

Ward Melville High School

The Remembering 9/11 High School Course

The Remembering 9/11 teaching unit was created to give educators a resource for incorporating this essential part of history into their lesson plans, whether through language arts, history, political science, or other subject matters. Children coming of age in this post-9/11 world are too young to remember the event, and thus often do not have a clear understanding of its ongoing impact on our world.

In collaborating with educators to develop curriculums that meet their needs, our program has identified three broad goals:

- Educate students, particularly those who are too young to remember 9/11 but mature enough to be educated about the event itself and its lasting social, psychological, and physical impacts, and encourage them to think about it critically from various angles
- Inform students and their communities about resources for those who were/are affected by 9/11, as mental and physical health issues continue to exist and be discovered
- Encourage the institution of teaching 9/11 in schools, particularly in the New York tristate area

Remembering 9/11 was originally piloted in 2013 at Ward Melville High School in a number of social studies classes. Part of educator Tracy Beauchamp's unit on "Great Moral Questions," the curriculum included debate about 9/11 and its ramifications, selected readings from *We're Not Leaving*, viewing and discussion of a 9/11 documentary, a Q&A with a number of WTC responders and a WTC program representative, and a wrap-up dialogue session on what the students learned not only from the unit material, but from the responders' firsthand stories and memories.

This program is an endeavor that grows with each passing year. We are now proud to offer educators a fully realized standalone unit free of charge. This high school level unit encourages students to ask thoughtful questions and analyze sources as empathetic historians. Lessons plans include thematic analysis of readings; comparing and contrasting September 11th with other major historical events; class debates; crafting written arguments; creating a narrative through interview; and more. This educational unit fosters critical thinking and writing skills, creativity, and encourages analytical exploration of many topics. The unit includes Common Core standards met for each lesson; sample student work; connections to other subjects and projects; and a plethora of other material to ensure that implementing it in one's classroom is not only simple, but successful.

We consider making 9/11 education available a vital component of our broader goals. In addition to the teaching unit and multimedia materials available for use, we offer an invaluable and singular opportunity for students to speak directly with 9/11 responders from all backgrounds—law enforcement, fire rescue, construction, medical professionals, and others. Witnessing how such education has shifted perspectives, opened new avenues of thought, and fostered a sense of civic duty in our youth has only increased our drive to help educators implement these kinds of curriculums into their larger lesson plans.

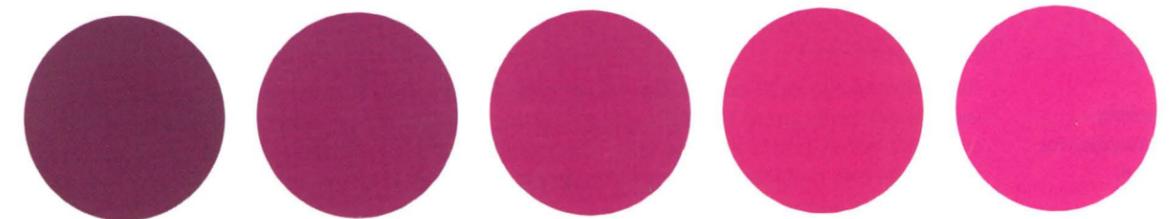
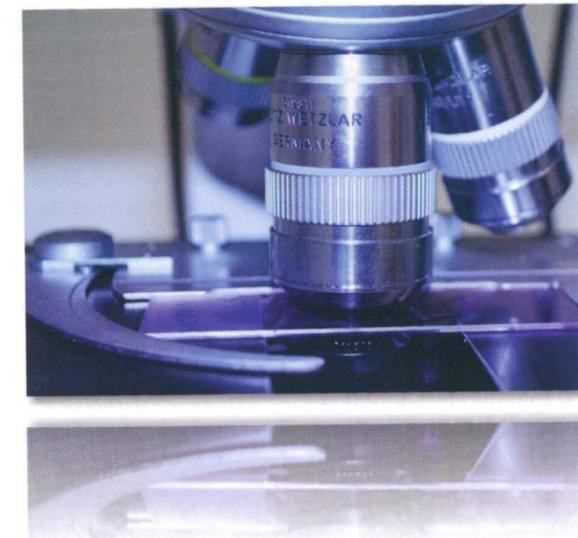
Research

Epigenetics
Lifestyle interventions
Health and wellness
Resiliency

Breaking Down Barriers to Care Through Research

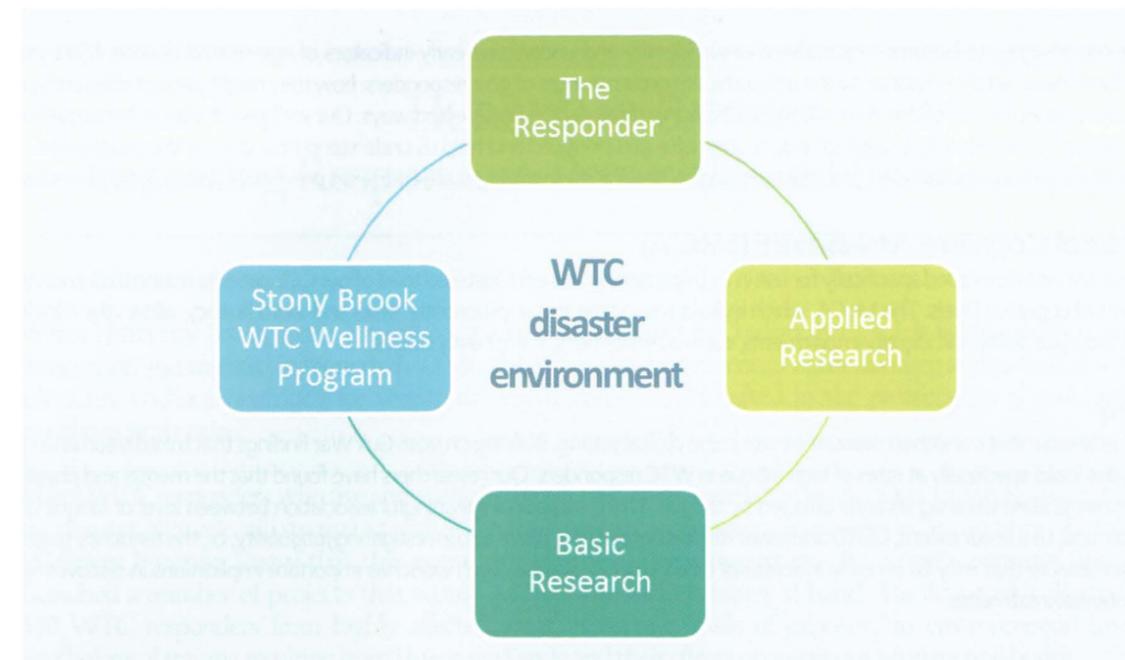
While monitoring and treating our member patients in the immediate, Stony Brook WTC Wellness places great importance on our research arm, with views to the long-term. Our program aims to comprehend the health consequences of 9/11 response work, including as yet unknown concerns—with particular attention to co-occurring, or “comorbid,” physical and mental health conditions. Utilizing the clinical setting is hugely important for our goals: the participation of our patients in work such as the Montreal Cognitive Assessment (MoCA), wellness assessments, and studies on fatigue allows us to bridge the gap between the exam room and the research lab to great effect. These factors help our medical care to be focused, and more importantly, valuable. Understanding how the ramifications of 9/11—from toxic exposure to PTSD—affects responders allows us to continuously adapt our model of care, finding novel approaches and making better-informed decisions about necessary treatments.

The multidisciplinary research program at Stony Brook WTC Wellness has secured millions of dollars in funding for a variety of groundbreaking studies, many of which are ongoing. Dr. Benjamin Luft, Director and Principal Investigator, has collaborated with renowned researchers including Drs. Evelyn Bromet (who was integral to the creation of our research program), Adam Gonzalez, Roman Kotov, Sean Clouston, and others. With experts spanning the fields of epidemiology, psychiatry, clinical psychology, biology, genetics, and medicine, our work to date has uncovered important links between 9/11-related illnesses, such as the meaningful relationship between PTSD and respiratory issues. Additional findings underline the fact that responders with conditions resulting from WTC exposures (such as sinusitis, various lung diseases, and GERD) may not respond as well to typical treatments. These discoveries have led to further investigations into epigenetics (where we are currently exploring differences in gene expression related to immune functioning), the significance of comorbid psychological and physical traumas, and strategies to increase wellness behaviors in our patients. Through the integration of cognitive behavioral therapy programs, we focus on promoting lifestyle changes that will positively impact disease trajectories and help our patients live healthier lives. The combination of our clinical discoveries and related research efforts has helped us develop an ever-evolving standard of care for our patients.



Our Research At a Glance

Project	Description of Research	Funding
The Burden of Mental and Physical Comorbidity in WTC Responders	3,054 WTC responders assessed between 2012-2014 with PTSD module of the SCID and the RIFT to evaluate long-term WTC-PTSD and its effects. Results: 17.7% of participants developed PTSD; 55% of cases were active PTSD. After adjusting for variables, PTSD was strongly associated with respiratory symptoms; poor self-rated health; negative WTC health risk perceptions/poor life satisfaction; impaired relationships; low resilience; and more. Study concluded that WTC-PTSD is a chronic condition with major health and psychosocial consequences that continues to require careful, sustained management.	CDC \$1.5 mil
A Life Course Approach to Integrating Trauma and Cognitive Aging: A Cohort of 9/11 Responders	Evaluation of 540 WTC responders for mild cognitive impairment; examining social and biological determinants of cognitive aging in WTC responders. Findings suggest that WTC responders (in particular those with current WTC-PTSD) are at increased risk for MCI.	NIH/NIA \$2 mil
The Efficacy of a Brief Resiliency Training Program for Hurricane Sandy Disaster Responders	120 Sandy disaster responders; adapting and testing the efficacy of the NIEHS Disasters Worker Resilience Training (DWRT) program with the goal of enhancing resiliency for protecting mental health before exposure to future disasters.	ASPR \$361,000
Longitudinal Study of Mental Health & Post-traumatic Growth in Responders & Community Members	250 Sandy/WTC responders and 250 community members; a one year follow-up study to assess mental health and post-traumatic growth post Sandy. This longitudinal project focuses on both responders and community members in an effort to better understand psychological resilience.	ASPR \$321,000
The Daily Burden of PTSD and Respiratory Problems in WTC Responders	200 WTC responders with varying levels of PTSD symptoms use smart phone technology to collect real-time data on PTSD, respiratory, and other symptoms three times/day. First study to assess PTSD and co-occurring symptoms in real-time to evaluate level of impairment, and determine the potential existence of mediators.	CDC \$1 mil
Deciphering Biological Linkages Between PTSD and Respiratory Disease in WTC Responders	Using existing sample of 237 WTC responders; this work builds off our findings that PTSD is not only associated with LRS but may contribute to development of symptoms and diminish treatment response. Using our epigenetic work, the study will extend analyses to identify the precise cells where these pathogenic relationships are occurring. First study to examine mechanisms contributing to comorbidity between PTSD and respiratory symptoms; findings will lead to development of better diagnostics and more specific treatment for this disease process.	CDC \$1 mil
Mind Body Treatment of WTC Responders with Comorbid PTSD and Respiratory Illness	~150 WTC responders with PTSD and respiratory symptoms; first randomized controlled trial to test the impact of an innovative mind-body treatment on comorbid PTSD and respiratory illness and PTSD (using the 3RP: Relaxation Response Resiliency Program); important implications for outcomes ranging from quality of life and healthcare costs to morbidity and mortality in WTC responders and the population at large.	CDC \$1.52 mil
Epigenetic Linkage Between PTSD and Respiratory Disease in WTC Responders	Between groups study testing an important biological pathway that could potentially explain link between PTSD and chronic lower respiratory symptoms in WTC responders. Of interest is pro-inflammatory cytokines and their role in the methylation of immune genes that lead to lowered immune function. Study compares methylation patterns in WTC responders with different phenotypes (PTSD/LRS; PTSD/no LRS; LRS only; asymptomatic). May elucidate etiologic pathway underlying this comorbidity, help identify biomarkers useful for diagnosis and development of effective treatments.	NIH \$1.5 mil
Effects of Hurricane Sandy on the Respiratory and Mental Health of WTC Responders	Sample of 550 WTC responders from areas highly affected by Hurricane Sandy; evaluation of levels of exposure to environmental toxins and psychological trauma and their effects on respiratory and mental health. Outcomes include identification of risk factors for post-disaster health problems and understanding of relationship between respiratory disease and PTSD.	NIEHS \$390,000
Enhanced Smoking Cessation Intervention for WTC Responders	Randomized clinical trial of 100 smokers with significant WTC-related PTSD symptoms; an eight-week program to test efficacy of smoking cessation treatments in combination with cognitive behavioral therapies, with continued monitoring. Adapting treatments in this way addresses two major risk factors for respiratory problems: smoking and PTSD; will improve population's pulmonary health.	CDC \$1 mil



The events of September 11th, 2001, created a toxic and damaging environment. Because of this, the responder's health needs are varied and still growing. There is a symbiotic relationship between the individual, our program, and our research efforts—they are inextricably connected.

A Seminal Investigation into Responder Health

The Burden of Mental-Physical Comorbidity

From the WTC Program's first iteration as a monitoring program (established by the CDC in 2002), records revealed a significant comorbidity of lower respiratory symptoms, PTSD, asthma attacks, and GERD amongst monitoring participants. This evidence was consistent with documented associations between physical and mental symptoms, but there was little existing research looking into comorbidity of such symptoms. Our center's research team embarked on a mission to discover how comorbidity of illnesses affects responders' quality of life; what mechanisms are at fault; and how best to coordinate medical and psychiatric treatment.

Ultimately, this study documented not only the association between mental and physical symptoms, but definitively determined comorbidity between them, as well as its impact on various elements of the responder's life and medical care. Discovering this relationship heralded a new era of care not only for our responders, but for any person with comorbid illnesses. *This study is truly the nucleus of our subsequent ongoing inquiries into the impact of WTC-related illness as well those exploring the most effective types of medical care and intervention strategies.* We're continuing to explore this link through epigenetic and genetic studies. Implementing an ecological model has helped reorganize our thinking about 9/11 health conditions, including what questions we attempt to answer through our research.

FINDINGS FROM THE SURVEILLANCE DATA OF THE WTC PROGRAM'S CLINICAL CENTERS HAS LED TO THE CONTINUAL EXPANSION OF THE LIST OF 9/11-RELATED CONDITIONS COVERED THROUGH THE PROGRAM. IN 2012 ALONE, MORE THAN 50 CANCERS WERE ADDED TO THE LIST.

From the Exam Room to the Research Lab

As the WTC patient cohort ages, it's become imperative that we identify and understand early indicators of age-related disease. More importantly, it's necessary to understand these factors in relation to the unique health circumstances of 9/11 responders: how they might present differently, affect existing conditions or in fact develop as a result of those conditions, and react to treatment in unexpected ways. Our wellness studies enhance patient monitoring tremendously, as they allow us to identify issues that might otherwise go unnoticed and help us understand how to slow the progression of age-related disease. It's the hope of our clinicians and researchers that our protocol becomes a model for state-of-the-art preventive care in general medicine.

Using the Montreal Cognitive Assessment (MoCA)

This cognitive assessment was developed specifically for use in a clinical setting; it is administered to all of our CCE patients during their monitoring visit and offers a measurement of cognitive levels. The MoCA, which includes assessments for visuospatial tasks and word fluency, allows the clinician to observe firsthand changes in cognitive ability and identify impairments, such as Alzheimer's, in their early stages.

Fatigue Severity

The self-report fatigue assessment is another measure we use in the clinical setting. Building on post-Gulf War findings that linked trauma to chronic fatigue syndrome in males, this looks specifically at rates of high fatigue in WTC responders. Our researchers have found that the mental and physical function of more than 21% of those studied were significantly affected by fatigue. There was also a meaningful association between level of fatigue and diagnosed PTSD and depression, and, to a lesser extent, GERD and lower respiratory disease. We're also investigating *fatigability*, or, the tendency to get very tired by everyday activities, a measure that may be an early indicator of inflammatory disease. Such work has important implications in discovering causation as well as identifying potential treatments.

Functional Assessments

Observing physical function is a critical tool in understanding age-related decline and how it relates to WTC responder health concerns. One simple assessment uses a dynamometer to measure an individual's grip strength, which is a strong biological indicator of risk for disease and physical impairment. Another employs a physical function battery developed by renowned researcher Dr. Jack Guralnik (University of MD, former National Institute on Aging, NIH), in which the patient's lower extremity functioning is tested with a brief set of sit, stand, balance, and gait commands. D. Guralnik's study found associations with self-reports of disability and prediction of mortality; this test takes only a few minutes but has profound implications.

Connecting New Technologies to Responder Health

Ecological Momentary Assessment Study (Daily Health Study)

As part of the groundbreaking research on the interplay between PTSD and lower respiratory issues, this study, with funding of \$1m, allows our multi-disciplinary team of researchers to collect real-time data on symptoms experienced by participants. Using smart phone technology, responders will record PTSD and respiratory symptoms three times daily; heart rate, cortisol levels, and respiratory inflammation levels will also be measured.

What's remarkable about this relatively simple change in data collection methods is that, for the first time, researchers are able to accurately assess daily symptom occurrence and level of impairment and determine the potential existence of mediators between these maladies—until now, documentation depended on patient recall during clinical visits and was, consequently, far less accurate. Comparing this information with other data will allow for more precise measures of prevalence and symptom severity and reveal findings on the biology of PTSD's relationship to respiratory illness.

In turn, our doctors and other clinicians will be better equipped to offer more effective diagnosis and treatment, serving both the immediate needs of our own patients while also addressing a primary mandate of the Zadroga Act and creating a framework to treat persons affected in similar ways by other disasters.



Describing the grip strength test.

HURRICANE SANDY: Impacting Responders Personally and Professionally

When Hurricane Sandy made landfall on the Eastern seaboard in October 2012, it left behind in its wake severe destruction and resulted in more than 100 deaths. Long Island experienced major flooding and powerful winds that left many without electricity for weeks, destroyed homes, and resulted in the proliferation of mold and other environmental toxins.

Many WTC responders who live and work in the affected areas were active responders to Sandy and/or victims to the disaster, all while still struggling with 9/11-related health consequences. [Researchers at the Stony Brook WTC Wellness Program knew that this event would have a grave impact on the center's patients, and so they launched a number of projects that would address the various issues at hand.](#) The first study collected data on 550 WTC responders from highly affected areas, evaluating levels of exposure to environmental toxins and psychological trauma resulting from Hurricane Sandy and their effects on respiratory and mental health.

Researchers soon embarked on a follow-up study in collaboration with other institutions, allowing two populations to be studied: disaster responders who were previously exposed to the WTC disaster and community members exposed to Sandy. This collaboration created a unique opportunity to better understand how individuals recover and grow from disasters; a key component of this study is a collection of videotaped oral histories detailing individual's firsthand accounts of the hurricane and related psychological impact. [This longitudinal study's innovative design and dynamic cohort allows for great strides to be made in the understanding of post-traumatic growth.](#)

Most recently, a third groundbreaking study with significant implications for communities far beyond those involved with the WTC disaster has emerged. Researchers are adapting and testing the efficacy of the NIEHS Disasters Worker Resilience Training (DWRT) program, originally designed for responders to the 2010 Deepwater Horizon oil spill. Most previous work in this area has focused on acute interventions, whereas this methodology is based on a number of empirically tested treatments to enhance resiliency in disaster workers before exposure to potentially traumatic events. [This cutting-edge work is the first randomized clinical trial to evaluate the efficacy of a brief intervention for resilience training in active responders; will strengthen future disaster preparedness, response, and recovery efforts; and provides a manualized training program that can be adapted for use with other disaster responders.](#) It is expected that three months post-intervention, participants will demonstrate lower perceived stress and greater posttraumatic growth; increased knowledge regarding potential mental health problems post-disaster; and an increased willingness to access mental health care.



Better Habits for Better Health: Lifestyle Intervention Studies

A Perfect Storm: Smoking and PTSD

While cigarette use is life-threatening in any population, it's particularly insidious to WTC responders, who characteristically suffer from persistent respiratory problems as a result of their work at the World Trade Center sites. Adding to this is the scientifically documented fact that quitting can be a particularly tough goal to achieve when an individual experiences symptoms of PTSD (or other anxiety disorders)—not only are they more likely to fail standard methods, but they're likelier to relapse. This combination of factors creates the perfect storm for our patient population—a significant number of whom have comorbid respiratory illness and PTSD.

Building on a decade of research collaborations on the links between anxiety and smoking, scientists at Stony Brook University evaluated a new method to help these responders with a smoking cessation intervention that also alleviates PTSD: the Enhanced Smoking Cessation Intervention for WTC Responders. With the participation of 100 smokers displaying significant WTC-related PTSD symptoms, the eight-week program offers half the participants standard smoking cessation treatments while the other half receive that therapy augmented by cognitive behavioral therapies using a protocol developed by Dr. Michael Zvolensky (director of the Anxiety and Health Research Laboratory and Substance Use Treatment Clinic, University of Houston). Its effectiveness is then measured for a subsequent six months' time by monitoring smoking abstinence, improvements in PTSD, and improvements in respiratory symptoms. This \$1.5m study is one in a cadre of new interventions pioneered by the Stony Brook WTC Wellness Program to address continued health and wellness with special attention to the population it serves.



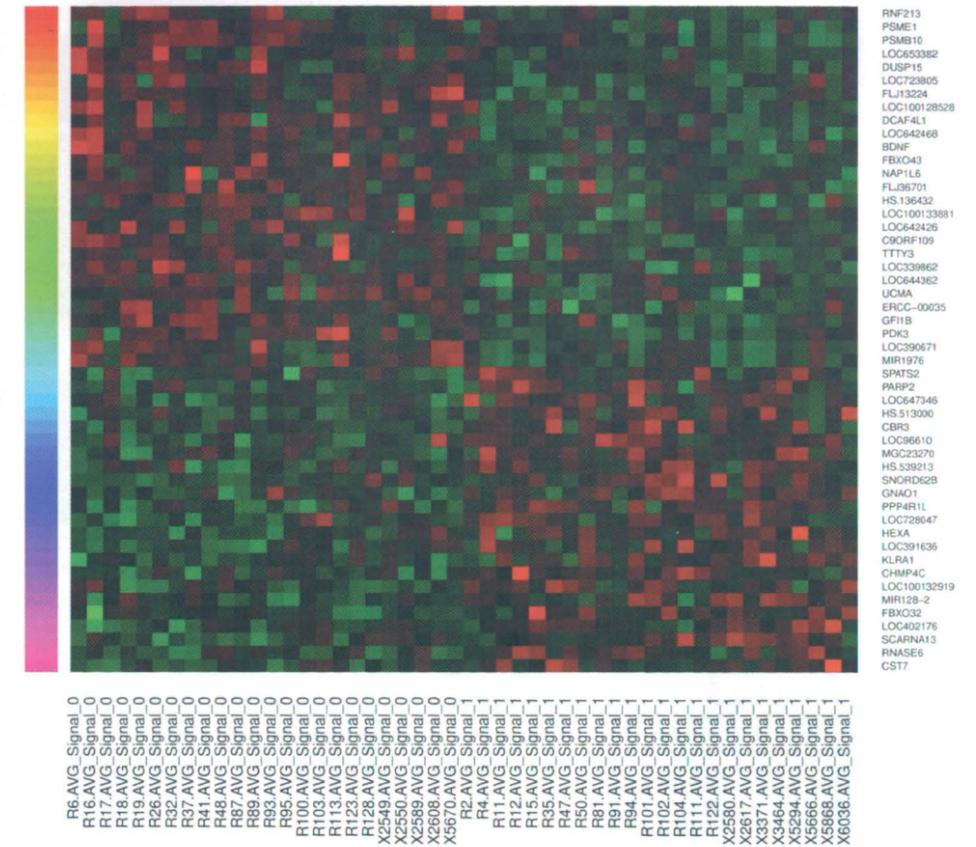
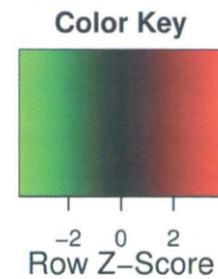
Maggie Bartlett/NHGRI

Exploring Healing Through the Mind-Body Connection

In spite of the specialized healthcare offered by our clinicians, many WTC responders continue to be affected by comorbid respiratory illness and PTSD. The Mind Body Treatment for WTC Responders with Comorbid PTSD and Respiratory Illness study directly addresses both the needs of these individuals and existing knowledge gaps by utilizing a pioneering treatment protocol specifically designed to focus on both problems. The cost-effective and valuable intervention (the Relaxation Response Resiliency Program—3RP—designed at Harvard by Drs. Benson and Park et al.) has been adapted to the needs of our responder population and involves relaxation training and the teaching of cognitive-behavioral skills.

While the 3RP is known for reducing psychological distress and physical problems, its effect on PTSD and respiratory illness specifically has never before been studied. In fact, this study is the first ever randomized controlled trial to test the impact of the 3RP: this has important implications for outcomes ranging from quality of life and healthcare costs to morbidity and even mortality in both the WTC responders and the population at large. Thus far, feedback from participants has been excellent.

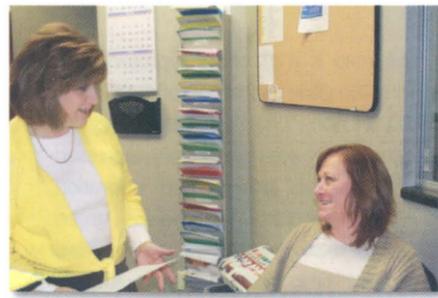
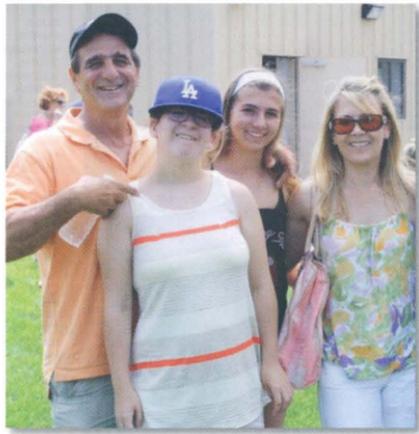
This heat map is a graphical representation comparing the gene expression of 48 patients (24 PTSD, 24 non-PTSD). The map shows the top 50 genes that are differentially expressed between the two groups. Red coloration denotes high expression, whereas green denotes low expression of the gene. These findings are promising, as they identify candidate biomarkers from gene expression that are associated with PTSD.



ON THE HORIZON: Federally Funded Research Exploring a Signature WTC Illness

In 2014, CDC/NIOSH awarded \$4 million in federal funding to our research program to conduct five new research projects that will evaluate the extent of mental and physical illness in hundreds of responders. Studies conducted by Stony Brook WTC Wellness over the past several years have revealed that as many as 60 percent of 9/11 World Trade Center responders continue to experience clinically significant symptoms of post-traumatic stress disorder (PTSD) and lower respiratory illness—the two conditions coexist so often in WTC responders that they can be thought of as one signature illness, say our researchers. This connection raises numerous important questions about the mechanisms underlying this relationship, and what they mean for disease progression going forward—these new endeavors will help us treat and monitor our responders more effectively in the long-term.

This ongoing work is the first to explore the association between gene expression and both PTSD and respiratory illness in 9/11 responders using cutting-edge epigenetics techniques. With the collection of blood samples, the researchers determined methylation patterns—a chemical process that contributes to changes in how genes are expressed as a result of environmental and other biological influences. The identification of these patterns is crucial to uncovering the biological mechanisms that underlie the genetic pathway linking PTSD and respiratory illness. In fact, we now know as a result of such work that trauma can silence or activate certain genes. This work's longitudinal design is allowing us to return to participants whose DNA samples were taken two years prior and assess whether biological mechanisms including methylation, gene expression, and levels of inflammatory cytokines contribute to onset and persistence of lower respiratory symptoms. Our work in this arena has led to significant conclusions, with the potential to illuminate how we can better treat patients suffering from comorbid illness, as well as pave the way for a new generation of diagnostic tests.

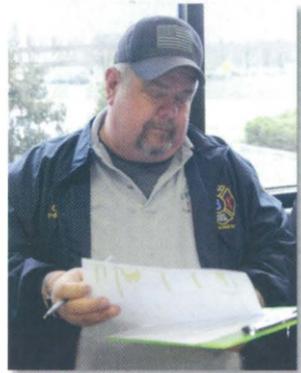


Looking Forward

Well over a decade has passed since September 11, 2001, and with it, endless changes in the lives of WTC responders and the care they need.

As caregivers, researchers, advocates, and educators, we have become witnesses to the brave and selfless actions of these men and women, and too often, to the consequences of those acts—which reverberate through the individuals, their families, and into the community at large. Therefore, we're passionate about making sure the very personal histories of our responders are recorded, shared, and used as a tool to educate future generations. The Remembering 9/11 Project and our education and library initiatives are cornerstones of this effort.

As the needs of our patients evolve, due to aging and other factors, so does the focus of our Center. Although we must address the emergence of new WTC-related illnesses, we have entered a phase of care that centers on preventive approaches and promoting resilience—attending to minor health



issues (both age-related and not) before they become more serious, educating our patients on healthy lifestyle choices, and more.

Our ongoing research efforts reflect this philosophy, with studies on epigenetics, comorbidity of illnesses, and others that teach patients techniques for stress management, smoking cessation, and more. We're also committed to using our expertise with this unique patient population to become a resource in providing care for the victims of large-scale disasters.

Continued growth and evolution is integral to the success of our work at Stony Brook WTC Wellness—we are committed to providing premier physical and mental healthcare; making new discoveries about gene expression and the long-term effects of a catastrophic event on those involved; and preserving the legacy of those individuals we serve.



Stony Brook WTC Wellness Program
WTC Health Program—Long Island Clinical Center of Excellence
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