### 2016-2017 YEAR IN REVIEW WORLD TRADE CENTER HEALTH PROGRAM



www.cdc.gov/wtc or call 1-888-982-4748



### A Message from Dr. John Howard, Administrator of the WTC Health Program

Our mission at the WTC Health Program is to serve you, our members. We know that you depend on high quality compassionate care for your 9/11-related health needs. Your experience with the Program, trust, and satisfaction are among our most important benchmarks for success.

Nearly 80,000 people are now enrolled in the WTC Health Program. In a year's time we've enrolled about 5,000 new members, and have seen a sustained surge in enrollments (data from July 1, 2016 through June 30, 2017). Clearly, the need for this Program remains strong.

As the WTC Health Program grows, we want to ensure continued high levels of service. This spring we mailed the 2017 member satisfaction survey. Thank you to all those who replied to the survey. Your feedback helps make the Program better for everyone. We regularly send this survey to all members to learn more about your experience with the Program and how we can better serve you.

The member satisfaction survey is just one way we are striving to improve the WTC Health Program. In this newsletter you'll learn more about the work we are doing, including a new benefits counseling initiative, an improved member handbook, and opportunities to interact with the Program online. You'll also learn more about innovative treatment offerings, our commitment to research, and how we are working to make research findings more accessible to you.

Finally, you'll read more about the personal stories that make the WTC Health Program such a vital and important service. It is our honor to assist you and we welcome your feedback.

In health,

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#### John Howard, M.D.



### New Services for Nationwide Provider Network

The Nationwide Provider Network, or NPN, is like a neighborhood health clinic with national reach. The NPN matches Program members outside of the New York City area with doctors, nurses, and counselors near their home or workplace. Nearly 11,000 responders and survivors across the country have joined the NPN. They receive the same high quality monitoring and treatment offered in the Clinical Centers of Excellence (CCE), but they interact with the Program from a distance.

Logistics Health Incorporated (LHI), which runs the NPN, seeks to lessen that distance. They have launched two new services to help members connect with the Program.

### LHI.Care

This secure mobile app allows members to manage aspects of their healthcare from the convenience of their phone. "We're providing a way to communicate with the Program in the way that people prefer," explains Mark Shay of LHI. The new app "cuts out the clutter. There's no calls, no waiting." Members can download forms, request appointments, and even chat with staff.

### Town Hall Tour

LHI has launched a national town hall tour. Members can meet their case managers, speak with preferred health providers, and learn more about pharmacy and other benefits. "Town hall meetings will help our members put names to faces," explains Holly Nickelatti of LHI.

After a well attended first meeting in Tampa, LHI is planning more events. NPN members can speak with their case managers to learn more about dates for the town hall tour or to sign up for LHI.Care. If you don't know your NPN case manager, call 1-888-982-4748 to be connected to LHI.

### Never Miss **a Refill!**

### Mail order pharmacy available for members

Do you take multiple medications?

Have a busy schedule?

Dislike waiting in line?

If you're a member of the WTC Health Program, mail order pharmacy may be for you!

The WTC Health Program, and its pharmacy partners Team MCA and Optum, have teamed up with national retailer Walgreens to offer mail order service. Mail order is an easy way to refill your WTC-prescriptions. Medications are discreetly packaged, shipped for free, and arrive promptly at your home. You'll have fewer trips to the pharmacy and less worry about missing needed medication. As a Program member, it's easy to sign up. Please call 1-855-640-0005, option 2, to speak with someone who can help.

Not interested in mail order? As a member of the WTC Health Program you also have access to a national pharmacy network of over 65,000 retail locations. If your pharmacist has any questions about processing medications covered by the WTC Health Program, please call 1-855- 640- 0005 Option 1, then 2.



### **Mind-Body Medicine** Study looks at the effects of relaxation practices on 9/11 health

The WTC Health Program supports dozens of innovative research projects about 9/11 health. Below is a profile of just one of these projects. To learn more about other research studies visit the Research Gateway at www.cdc.gov/wtc

Many members of the WTC Health Program have more than one certified condition; for example, asthma and PTSD or GERD and depression.

"These conditions aren't experienced in isolation," explains Dr. Adam Gonzalez of the Stony Brook University Clinical Center of Excellence (CCE). Research shows, for example, that a person with 9/11-related PTSD may have more severe breathing problems than someone without PTSD.

### What if there was an effective therapy to help with multiple conditions at once?

This question is at the heart of an innovative research study at the Mind-Body Clinical Research Center at Stony Brook University. The Stress Management and Resiliency Training Program (SMART) teaches 9/11 responders how to decrease the physical and emotional effects of stress. Chronic stress may prime the immune or inflammatory systems to cause or exacerbate disease. Mind-body medicine teaches people how to manage chronic stress and lessen its toll.

The SMART Program is an 8-week training based on research from the Benson-Henry Institute for Mind-Body Medicine at Massachusetts General Hospital. Participants in the SMART Program meet each week to learn different techniques to elicit the relaxation response like deep breathing exercises, yoga, meditation and ways to change how you think about yourself, others, and daily experiences. Previous research shows that these techniques can improve sleep, help digestion, and reduce anxiety. Dr. Gonzalez, whose father was a 9/11 responder, wants to understand if relaxation practices like yoga, meditation, and other adaptive coping skills can help responders manage their health, especially among those who face more than one condition.

"We try to take a broader overall approach to care," he states, "one that targets both physical and mental health." His study is measuring the effectiveness of the SMART Program by comparing responders who practiced SMART techniques to individuals who received more general health behavior coaching.

Dr. Gonzalez states that the therapies "have been very well received." Study members "report feeling better and doing better. They are seeing the impact of practicing these techniques."

The group also benefits from social connectedness with other 9/11 responders. "The groups offer a shared space where members can spend time and learn new skills with others who understand their experience," he explains.

Dr. Gonzalez and his co-investigators, including Drs. Benjamin Luft, Evelyn Bromet, Roman Kotov and Brittain Mahaffey are finishing the results of the study and plan to publish their findings. He is also working with a team of investigators at the NYU/Bellevue WTC Survivor program to translate and evaluate the program in Spanish.

### **Research to Care**

### Helping members learn more about 9/11-related research

The WTC Health Program provides more than expert healthcare. It's also a major sponsor of research into the health effects of the September 11th terrorist attacks. The Program now funds dozens of projects, studying topics like cancer, biomarker development, and mental health disorders.

Scientists funded by the WTC Health Program help drive our "Research-to-Care" approach, which ensures that study findings benefit those with 9/11-related illnesses. "There is a lot of passion from our researchers," explains Dr. Max Lum, the co-creator of the Research Gateway, a new online library of studies sponsored by the WTC Health Program. Researchers have a personal passion for their work. Many are also doctors seeing patients with 9/11-related conditions like asthma, PTSD, and GERD.

Now, with the launch of two new projects, members will have more access to research and an opportunity to interact directly with the scientists. Dr. Lum explains that the goal of these projects is to share "the research that we're doing in a way that people can understand and relate to in their own lives."

### **Research Gateway**

The Research Gateway is a searchable web tool that has all studies sponsored by the WTC Health Program. The website uses over 150 common key words to make it easy to find information. Interested in knowing more about 9/11-related PTSD? Simply type "PTSD" in the search box and you'll find a list of related studies. Users can read summaries of research projects, download full articles, and even watch brief videos of researchers explaining their work. To see more, go to www.cdc.gov/wtc and click on Research Gateway.

### Research to Care Community Engagement Event (Free) Saturday, October 21, 2017 8:30 AM - 4:00 PM NYU Langone Medical Center 550 First Ave, New York, NY 10016

### **Research to Care: Community Event**

What do we know about health effects from the September 11th attacks? What issues are emerging? What treatments are effective? And how can I be more involved with supporting research?

Join us for answers to these and other questions at our first ever Research to Care Community Engagement Event. This **free** event will occur on October 21, 2017 from 8:30 AM- 4:00 PM at NYU Langone Medical Center. Researchers with the WTC Health Program will be there to answer questions from members and present findings on a range of 9/11-related disorders. The event is open to all members and their families. To learn more and complete your free registration, go to **https://wwwn.cdc.gov/ResearchGateway/R2C/Register** 

### Thank you to members who make 9/11 health research possible!

Thank you to members who choose to share information about their symptoms with researchers during their annual monitoring exams. Your participation provides valuable insight to the link between 9/11 exposures and health effects. Participation in research is voluntary and anonymous – your identity is never revealed. You can also choose not to disclose your health information and still receive your monitoring exam and treatment for certified 9/11-related health conditions. For more information, talk to your WTC Health Program provider.

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## A Better Ouality of Life

### By Michelle Wotowiec Mount Sinai Clinical Center of Excellence

Paul Gerasimczyk, a member of the WTC Health Program, has been coming to the Mount Sinai WTC Clinical Center of Excellence regularly since he enrolled in 2004. A former New York City police officer, Paul was with his partner at the corner of Broadway and Vesey Street when the first building came down. He remembers trying to reach his sergeant who had been assisting people with injuries at World Trade Center Plaza. Tragically, his sergeant died in the building collapse. From that moment through Saint Patrick's Day 2002, Paul's unit dedicated each day to supporting the recovery and clean-up of Ground Zero.

### Member Storv

Paul describes the first time he started coughing and couldn't stop. "Little beads of sweat broke out all over my face," he recalls, "I didn't know that I was sick." It was not until 2004 that one of his coworkers told him about the World Trade Center (WTC) Screening Program at Mount Sinai. "My friend appealed to my better judgement – he told me to go and get examined and if I'm okay, they'll tell me I'm okay. If there is something wrong, though, they can help me. It made sense." Paul continues, "The doctor at Mount Sinai was the first to tell me the coughing was asthma attacks. They then discovered I had Chronic Obstructive Pulmonary Disease and Reactive Airway Dysfunction Syndrome." In 2007, the doctors found a tumor in Paul's kidney. "I was fortunate," Paul says, "I had the kidney operation done at Sloan Kettering where I had a great experience. I was very lucky that the cancer was caught on time."

### "You have to make time for yourself in order to be well and help others."

Paul recommends that all responders who are not already enrolled in the WTC Health Program take the time to enroll, regardless of whether or not they feel sick. "The doctors in this Program are specialized in recognizing the illnesses and injuries that are related to the WTC site. The regular physicians outside of the Program, while they are trained to recognize illnesses, they don't specialize in discovering and detecting illnesses that are unique to 9/11 first responders." Paul wants all responders to know that you can complete your annual exam in one day and in one place. "You have to take the time out to do this for yourself," he says, "You have to do it for your family."

Paul reports that his experience with the WTC Health Program "... has been A+. It's great—everything from the doctors to the staff." In addition to his treatment appointments and annual monitoring visits, Paul regularly attends the monthly WTC Mindfulness/Stress Reduction classes at Mount Sinai Hospital. "I heard about Mickie Brown's classes through my WTC doctor," he explains. The classes are open to all Mount Sinai's WTC Health Program responders, free of charge. "Taking this class is doing something for yourself—almost in a spiritual way. It helps you center yourself and has a positive effect on your psyche and physical well-being. It helps you relax and heal. You have to make time for yourself in order to be well and help others," Paul explains.

Paul acknowledges that participating in the Program requires effort on his part. He has to schedule and attend his appointments, committing a few hours of his day to complete his visit. For Paul, however, there is no question as to whether or not taking these steps is worth it. "The decade I have spent with the Program has helped me in ways you just can't quantify. They helped me extend my life through the yearly exams and through the prescribing of the medications." Paul also takes care to note that his continuous participation in the Program is not only about his own health: "I feel that I am helping future generations who may become sick due to similar exposures." When reflecting on his experience with the WTC Health Program, Paul says, "They gave me a better quality of life."

Thank you to the Mount Sinai Clinical Center of Excellence for sharing this inspiring story with us! Mr. Gerasimczyk's experience reflects the high quality, compassionate healthcare available at all of our Clinical Centers of Excellence and through the Nationwide Provider Network. To locate a clinic visit www.cdc.gov/wtc or call 1-888- 982-4748.

# PISION A Flaw.

It can come from facing situations MOST PEOPLE FEAR.

### Spotlight on 9/11 Health

### **PTSD** Awareness

Post-Traumatic Stress Disorder (PTSD) is one of the most commonly treated conditions in the WTC Health Program. PTSD can occur following a dangerous, frightening, or shocking event, like the September 11th terrorist attacks. It is normal to feel fear or stress after this type of experience, but when these feelings interrupt daily life for weeks or months after the event, a person may have PTSD.

PTSD symptoms usually start early, but sometimes they can begin years afterward. Common symptoms of PTSD include:

- Flashbacks
- Bad dreams
- Frightening thoughts
- Avoiding places

- Avoiding thoughts or feelings
- Being easily startled
- Feeling tense or on edge
- Trouble sleeping
- Angry outbursts
- Negative feelings about oneself
- Feelings of guilt or blameLoss of interest in enjoyable
- activities

The WTC Health Program has teams of experts that can help members manage PTSD. They see thousands of people with PTSD and know which treatments may be able to help. In addition to seeking care from the WTC Health Program, the following tips developed by the National Institutes of Health may help with self-care:

• Engage in gentle physical activity or exercise to help reduce stress.

- Set realistic goals for yourself.
- Confide with a trusted friend or relative.
- Break up large tasks into small
- ones, set some priorities, and do what you can as you can.
- Try to spend time with other people. Tell others about things that may trigger symptoms.
- Expect your symptoms to improve gradually, not immediately.
- gradually, not infinediately.
- Identify and seek out comforting situations, places, and people.

Source: National Institute of Mental Health www.nimh.nih.gov/health/ topics/post-traumatic-stressdisorder-ptsd/index.shtml

### It Takes a Team

### Mental health treatment in the survivor program

All Clinical Centers of Excellence (CCEs) and the Nationwide Provider Network (NPN) offer extensive mental health treatment services. Below is a profile of the mental health team at NYC Health + Hospitals System WTC Environmental Health Center. It offers a glimpse of the high quality care available at all of our CCEs and the NPN.

"One of the main goals of our program is to meet people where they are," explains Dr. Rebecca Rosen, director of mental health treatment services for the WTC Environmental Health Center. This CCE serves members in the survivor program at the NYC Health + Hospitals System's Bellevue, Gouverneur, and Elmhurst Hospitals.

"At the survivor program we work very hard to understand each of our patients, as unique as each one is," says Dr. Rosen. "We have a wide variety of mental health services to best meet the particular needs of each survivor." "The services we offer," explains psychologist Dr. Paul Park, "include individual psychotherapy and different kinds of group therapy or any combination of these treatments depending on a patient's need." Psychotherapy can be an effective treatment for conditions like PTSD, anxiety, or trouble sleeping. Sometimes, however, a member may need more treatment options.

"When patients would benefit from medications to help with their symptoms or sleep difficulties, they can also see one of our psychiatrists," says Dr. Sukumar Rao, one of the team psychiatrists. This team approach helps make coordinating care easier for members. The mental health team meets weekly to coordinate patient care, and when needed, consult with the member's medical providers at the CCE. The goal is to develop a holistic treatment plan that considers emotional, medical, and practical life needs.

For example, If members "are worried about getting evicted," explains social worker Carol Burton, "we try to help them with that concrete stressor." Such day-to-day challenges are often at the forefront of a treatment session. Members may discuss medical, work, or relationship stressors, and can set the pace for the discussion of their 9/11 experience. Treatment sessions focus on learning skills and finding resources to live life with greater ease. "We're geared towards helping people regain functional capacity... to help people get back on their feet," says Dr. Priyanka Uphadyaya, one of the psychologists on the team.

Mental health treatment can also help people feel less alone. Assistant mental health director and psychologist Dr. Lucia Ferri explains that group therapy is popular because it "provides a caring environment in which patients can feel heard and understood by others in their struggles." Even survivors without certified mental health conditions can benefit from group support. The CCE offers free stress management and relaxation workshops for all survivors.

"People really feel like there is a home for them here," says Dr. Rosen.

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### 9/11 Health Trainings Now Available on WTC Health Program Website

The WTC Health Program offers trainings for healthcare providers, researchers, and the general public about 9/11-related physical and mental disorders. The series features doctors from the WTC Health Program and other experts in 9/11-related healthcare. The trainings are appropriate for anyone who wants to learn more about 9/11 exposures and health effects. Professionals can receive CME/CE for taking the trainings.

Visit https://www.cdc.gov/wtc/training.html to learn more. There is no need to create an account to view the trainings. If you want to receive credit for taking the trainings you must create an account on CDC's Training and Continuing Education Online (TCEO) site https://www2a. cdc.gov/tceonline/ to take the post-test and receive a certificate.

### Improved Member Handbook Now Available

The member handbook is your guide to the benefits and services offered by the WTC Health Program. We recently updated the handbook with new features, such as an improved table of contents and glossary to help you find the information you need quickly and easily. The new handbook is online at http://www.cdc.gov/ wtc/handbook.html where you can read it or download a copy. If you'd like a printed copy please e-mail wtc@cdc.gov or call 1-888-982-4748 and we will send you one in the mail.

### **Expanded Benefits Counseling**

As a member of the WTC Health Program you may be eligible for benefits from other programs that serve the 9/11 community. This year we've launched new resources to help streamline benefits counseling for members. Ask your WTC Benefits Counselor for more information. This person may have different titles depending on your clinic, such as a social worker, case manager, or other designated staff person. If you need help finding a WTC Benefits Counselor, ask a staff person at your clinic to help you.

#### What can I expect at my benefits counseling visit?

Your counselor will ask questions to help identify which benefits you may be eligible to receive. He or she may ask about your 9/11-related exposures, health conditions, finances, and employment.

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#### What types of benefits can my counselor help me find?

- Your benefits, services, rights, and responsibilities as a WTC Health Program member;
- Workers' compensation benefits;
- September 11th Victim Compensation Fund (VCF) assistance;
- Disability benefits;
- Food, utility, housing, or transportation;
- Cancer-related benefits for you and/or your family; and
- Available benefits for your medical, mental health conditions, and/or medications not covered by the WTC Health Program.

For more information, talk to your Program provider or call the WTC Health Program at 1-888-982-4748.



Katie Howard helps members and applicants with enrollment and appeals.

#### How do you help people who are members of the WTC Health Program?

Much of my work is done behind the scenes. I handle the enrollment and eligibility of the new applications, meaning I review every new application that is submitted to determine whether or not an applicant can be enrolled into the Program. I also serve as the Appeal Coordinator for the Program. This means that I process all incoming appeals and serve as a point of contact for members should they need any personal assistance from me.

#### How does the appeals process work?

The appeals process is pretty straightforward and explained initially when a member receives a denial letter and more extensively on our website. A member can appeal a denial of enrollment, a denial of a certification of a health condition, or a denial of a treatment for a certified health condition. The denial letter that is sent to the member will explain that the member has an appeal right and provides the address or fax number to send their appeal to as well as the timeline in which it must be submitted. Once an appeal is submitted by the member, it is forwarded to me for processing. I will determine whether or not the appeal is valid and can move forward for processing.

In order for an appeal to be valid it must be submitted in writing within the timeframe specified in the denial letter. The appeal must also clearly identify the appellant and the reason(s) for the appeal or why the member feels the denial was incorrect. Once the determination is made that the appeal can move forward, I will notify the member in writing (this letter includes all of my contact information as well). The appeal is then sent to a Federal Official (FO) who is outside of and independent of the WTC Health Program. The FO will make a recommendation, which is sent back to me. I provide the recommendation to the Administrator for final decision. Once a final decision is reached, I send the decision documentation to the appellant. If there are



questions or concerns during the appeal process, the appellant can contact me and I will do my best to answer any questions and walk them through the process.

#### Any helpful tips for members on how to get the most out of the WTC Health Program?

I would encourage members to visit and explore our website (www.cdc. gov/wtc). It contains a lot of great information and resources. Also, I would encourage the member to take advantage of the monitoring exams that the CCE or NPN offer, and to share all of their concerns, symptoms and any previous medical records that they have. And use the social workers and/or benefits counselors within the CCE or NPN to understand benefits and have your questions answered.

#### What do you like best about your job?

I really enjoy the people that I work with. My co-workers are engaged, intelligent and do their best work to make this Program helpful and effective for its deserving members.

VTC HEALTH PROGRAM 2016-201

### World Trade Center Health Program

Patriots Plaza I 395 E Street SW, Suite 9200 Mailstop P12 Washington, DC 20201 FIRST-CLASS MAIL POSTAGE & FEES PAID PHS/CDC Permit No. G-284

### World Trade Center Health Program Locations



The Nationwide Provider Network provides care to members outside of the New York City area. For more information please call 1-888-982-4748. • General Responder Clinical Centers of Excellence

#### ICAHN SCHOOL OF MEDICINE AT MOUNT SINAI

Selikoff Centers for Occupational Health Telephone: 1-888-702-0630 Locations: Manhattan and Staten Island

#### NEW YORK UNIVERSITY SCHOOL OF MEDICINE

Department of Occupational and Environmental Medicine Telephone: 1-212-263-7335 Location: Manhattan

THE QUEENS WORLD TRADE CENTER HEALTH PROGRAM, Northwell Health Telephone: 1-718-267-2420 Location: Queens

#### STATE UNIVERSITY OF NEW YORK, STONY BROOK

Telephone: 1-631-855-1200 Locations: Commack and Mineola

#### RUTGERS UNIVERSITY

Robert Wood Johnson Medical School Environmental & Occupational Health Sciences Institute Telephone: 1-848-445-0123 Location: Piscataway, New Jersey

### • Fire Department City of New York (FDNY) Clinical Center of Excellence

FDNY Bureau of Health Services Telephone: 1-718-999-1858 Locations: Brooklyn, Staten Island, Bayside, Brentwood, Middletown, Commack, and Manhattan

### • Survivor Clinical Center of Excellence

NYC HEALTH + HOSPITALS

Telephone: 1-877-982-0107 Locations: Bellevue Hospital, Gouverneur Healthcare Services, and Elmhurst Hospital Center