HEALTH EVALUATION

Non-covered conditions

It is of paramount importance that these illnesses be added to the covered conditions:

Cancer

1. The attacks on the Twin Towers spewed more than 1.8 million tons of hazardous contaminants into the air and set off massive fires that polluted Lower Manhattan for months
2. The result was unprecedented exposure to combinations of known and suspected carcinogens
3. It is therefore not surprising that record numbers of cancers have been reported among the 9/11 community
4. Cancer is an absorption disease, and the toxins from WTC exposure were absorbed through the mouth, nose and skin
5. The addition of cancer to this list needs to be fast tracked
6. In the case of cancer, we cannot wait for "science as usual"

The following is a list of the cancers that have the highest incidence of occurrence in our community:

Skin	Lung	Lymphoma	Liver	Colon	Thyroid
Testicular	Leukemia	Melanoma	Brain Cancer	Kidney	Bone
Throat	Breast	Stomach	Laryngeal	Tongue	Rectal
Esophageal	Myeloma	Pancreatic	Sarcoma	Tonsillar	Sinus and Nasal
Gall Bladder	Neurological	Cervical	Eye	Adenocarcinoma of the Esophagus	Digestive Gastrointestinal
Muscular Skeletal	Anal	Ovarian	Mesothelioma	Parotid	Small Intestine
Parathyroid	Penile	Pituitary	Urethral	Bladder	Genitourinary
Gynecological					

Other conditions

1. Kidney disease
    a. Can lead to kidney cancer
        i. Resulting in kidney failure and the need for dialysis and kidney transplant
        ii. This We know that heavy metals are filtered through the kidneys
        iii. Therefore it is not surprising that we have seen an increased rate of incidence in kidney ailments within the 9/11 community
2. Neuro-developmental disorders
    a. There is a research study linking WTC *in utero* exposures to mild to moderate neuro-developmental problem[1]
3. Thyroid disorders
4. Neurological disorders
5. Immunological disorders
6. Inflammatory and connective tissue disorders
7. Blood disorders
8. Skin disorders

Post Traumatic Stress Disorder (PTSD)

1. We urge NIOSH to advise the US Department of Justice that:
    a. In 2006 the Surgeon General recognized PTSD as a physical injury because of the stress that it causes mentally and physically on the body.
    b. The yet-to-be-appointed Special Master of the Victim's Compensation Fund should recognize PTSD as a separate compensable condition.

[1] Megan D. Nordgren, Eric A. Goldstein, and Mark A. Izeman, "The Environmental Impacts of the World Trade Center Attacks: A Preliminary Assessment," *NRDC*, Feb. 2002, http://www.nrdc.org/air/pollution/wtc/wtc.pdf.

Medical Monitoring and Treatment

We urge NIOSH to ensure that there is an agreed upon, consistent quality of medical care and treatment provided to all participants in the WTC Health Program (WTC HP).

We are particularly concerned with:

Attributing illnesses to WTC Exposure

1. We ask NIOSH to:
    a. Use the same approach as NY uniformed services (e.g., the NYPD) regarding attribution of illness and symptoms to WTC causes:
        i. Evaluation begins with the premise that all symptoms and diagnosed conditions are WTC-related, until proven otherwise.

    b. Make sure doctors are well informed about which conditions are already on the NIOSH list of covered conditions or when a condition has already been linked to WTC exposure in published medical research

Consistency of Treatment

1. Participants who are communicating identical symptoms during the monitoring process at each Center of Excellence (CoE) must be treated in the same consistent manner
    a. Disparities among treatments offered by physicians at the various CoE's must end
    b. Disparities in the determination of program eligibility based on reported symptoms and conditions must end

2. Participants need to be treated holistically at one Center
    a. The practice of referring patients back to their own doctor for certain symptoms/ailments rather than being treated at the Center must be reconsidered

Consistency in Evaluation:

1. A consistent standard for evaluating symptoms and ailments needs to be established and followed in all Centers of Excellence administering and programs

Competency in Documentation and Related Administrative Paperwork

1. Medical practitioners must have a comprehensive understanding of the paperwork necessary to qualify participants for disability claims

2. The medical staff should have the knowledge, time and administrative support necessary to aid participants in determining and submitting appropriate certifications for applying for disability benefits

3. We know of instances where participants who should have been receiving a C-4.3 from the time that it was determined they had reached their Maximum Medical Improvement, had all the while been receiving a C-4.2
    a. This is a major life decision: a C-4.3 is needed to prove the "permanence" of one's conditions and has to be presented at a Workers Comp hearing to establish such permanence.

Advanced Diagnostics

1. Due to the 9/11 Community's unique exposure to an unprecedented brew of toxins, and the mandate of this research and monitoring program, participants should be given blood tests that are more sophisticated in evaluating toxins, inflammatory, and auto-immune conditions

2. Blood and urine tests should include screenings for cancers, where such tests exist

Participant Care and Communication

1. Choosing Physicians
    a. Participants should be able to choose their doctor and have a reasonable process by which to change doctors

2. Comprehensive Tracking and Integration of Records
    a. Participant records within the monitoring and treatment programs should be cross-referenced when the doctor is evaluating their conditions
    b. All symptoms should be consistently recorded electronically in participants' charts and tracked and analyzed.
        i. For instance, in the treatment program, participants' conditions other than WTC-covered conditions are recorded, though they are not analyzed or included in the research
            1. In the monitoring program they are not recorded

3. Timely reporting of test results
    a. CoEs must inform participants of test results in a timely manner, enabling participants to access treatment without delay
    b. Most medical practitioners provide test results within 7 to 10 days

4. There needs to be intercommunication among the CoEs
    a. CoEs must share information

Participant Accommodation

1. The World Trade Center Health Program needs to be patient-centered
    a. The visit should be designed in a way that decreases stress and promotes the well-being of the patient, as much as can be possible during a medical visit
    b. Participants should be treated with dignity and respect

2. Recommended itinerary of the appointment
    a. Blood tests should be done first to accommodate people fasting beforehand
    b. Psychological evaluations should be done early on in the appointment so that disturbing emotional feelings that may be triggered can be addressed while the participant is still at the CoE

3. There should be ample staffing so that optimum service can be provided

4. Follow-up appointments
    a. Some participants require multiple appointments because they need to see their regular doctor as well as a specialist
    b. Participant requests that multiple appointments be scheduled on the same day to avoid making multiple trips should be accommodated
    c. When follow-up appointments are required by specialists, the staff should take care of such appointments for, and communicate their necessity to, the participant ASAP
    d. Scheduling should be coordinated to best meet the needs of the participant
    e. If the participants' medical issue is urgent, a follow-up appointment should be scheduled without delay
    f. There has to be enough staff to monitor follow-up appointments
    g. Once the appointment is set, verbal communication should be made to the participant

5. Communication with staff
    a. Participants should have the opportunity to speak with a live individual when they communicate with staff
    b. When engaging in communication through voicemail and email, participants have a reasonable expectation of being able to communicate in a fluid manner and of a prompt reply

6. Referrals
    a. A referral is required for every visit with a specialist, including follow-up visits
    b. Once a participant has been referred by the treating doctor, the participant should be able to make follow-up appointments directly with the specialist
        1) Currently, the scheduling of all appointments has to be done through the treating doctor

7. Overall problems
    a. We expect something more than a bare bones program
        1) We ask that enough resources be provided to fund a first class program

8. Bedside manner
    a. Our community was involved in an unprecedented environmental and psychological incident, and we are battling significant physical and emotional conditions
    b. We ask that doctors and staff demonstrate the appropriate sensitivity and compassion when dealing with our unique community

9. Appointment duration
    a. Although the literature states that the exams take 3 hours, this does not accord with reality
    b. The exam takes close to 5 hours and is an all day event
    c. People cannot necessarily return to work, as they have promised their employer
    d. Please communicate clearly the duration of the exam

10. There should be late night and Saturday appointments, at least once a month, in order to accommodate those for whom it is too burdensome to take off of work

11. Benefits coordinator(s)
    a. There should be a benefits coordinator who would be responsible for assisting participants in obtaining all the benefits for which they may be eligible, e.g., disability, compensation, scholarships, etc.
    b. In this way participants do not discover available benefits after the point at which they were desperately needed

Data Collection and Analysis

Data Collection

All Data Centers (DC) should operate in a fully transparent manner using standard protocols to capture data on patient medical history, including WTC exposures and post-9/11 health effects for the populations that they serve.

1. Comprehensive data
    a. In order for the medical understanding of WTC illnesses to keep pace with the emergence of new health effects, comprehensive health data must be kept for each participant
    b. This list includes:
        i. Intake and Monitoring Visit data
        ii. Data from WTC monitoring medical exams
        iii. Data from WTC HP doctor visits
        iv. Data from non-WTC HP doctor visits

2. Intake and Monitoring Data
    a. Data should be input in electronic form
    b. Data from intake and monitoring questionnaires should be immediately printed out in order for the participant to check that data has been captured accurately
    c. Optimally, errors caught on first review should be corrected on the spot
    d. In addition, there should be a 2-week period for participants to review the document for any additional errors, which would be corrected by DC staff prior to the finalization of the intake/monitoring document being entered into the official record

3. Medical monitoring exam and doctor visit data
    a. Medical monitoring exam data and WTC doctor visit data should include information on all symptoms, illnesses and diagnosed conditions – whether or not these are deemed to be WTC-related
    b. Data should be entered electronically (not handwritten) and should be printed out and provided to the patient at the end of the visit
    c. Any unusual medical conditions the participant is experiencing that day should be noted in the record
        i. This could skew not only the participant's results, e.g., giving a false positive, but also skew the data used for the research at large

Tracking conditions

1. Each Data Center (DC) must maintain a centralized database with all monitoring data and diagnosed conditions:
    a. Whether or not the participant's condition is deemed to be WTC-related and
    b. Whether or not the diagnosing doctor is a WTC HP clinician

2. From this data, DCs must produce periodic reports on illness incidence and prevalence for conditions emerging in their participants
    a. The participants need to know which conditions are manifesting in significant numbers within the community

3. Updated incidence and prevalence data for cancers and other serious conditions diagnosed in the population should also be presented in graph form and shared with participants:
    a. Upon request, when they come for appointments and in newsletter form

Preferred Model

Data Centers should operate on a Community Based Participatory Research model (CBPR)

1. According to the website of the Harvard Clinical Translational and Science Center,
    a. "Community-Based Participatory Research (CBPR) is an emerging orientation to research which involves scientific inquiry that equitably involves both community stakeholders and investigators at all levels of the research process from design to dissemination. CBPR involves a partnership between the community and the investigator(s) where each group shares equal ownership of the process and products of research collaboration."

2. The 9/11 Community has a direct stake in the ongoing collection and analysis of data gathered on their WTC exposures and their health
    a. A CBPR partnership with DC investigators will ensure best results because:
        i. The whole community will remain invested in participation in the monitoring program and
        ii. because the collaboration between DC experts and the community will produce health data that best addresses the unmet health needs of the affected populations

Scientific Analysis

1. If CoEs will only evaluate and record those symptoms and diagnosed conditions on the covered list, their data will be flawed and inadequate
    a. This does not meet the standard of scientific rigor
    b. Further, this flawed data will produce flawed scientific research and undermine the effort to identify new conditions as WTC-related
    c. This does not serve the needs of our community

Research

Research Agenda

1. The research agenda should operate as a CBPR process

2. Our community should have meaningful input into proposed areas of study, research design, recruitment of subjects, data analysis and the writing of reports and articles

Current Research Gaps

1. Research non-covered conditions emerging at increased rates, including:
    a. Research reproductive abnormalities such as early sterility, infertility, early menopause, early gestation pregnancies and low birth weight in babies

2. Secondhand exposure/Next generation exposure
    a. Research first responders' children and spouses, who now have illnesses resembling those of the responders, and examine what secondhand exposure has done to them
    b. Research the incidences of affected children of male first responders whose partners conceived 1-2 years after the men were exposed
    c. We are hearing of cases of children who fall into these categories who have asthma, sleep apnea, severe ADHD, et al.

Integrative Medicine

1. We are concerned that integrative treatment and alternative medicine will not be covered in the Act

2. Many current participants in the WTC medical program have developed chronic illnesses and have reached a point where their health is no longer continuing to improve, i.e., the Maximum Medical Improvement

3. Many responders and survivors report significant gains in their health and quality of life as the result of pursuing an integrative approach to treatment, which includes alternative therapies

4. It is essential that there be a serious commitment to research funding for the study of integrative medicine and alternative treatments for WTC-related illnesses

5. We want the Act to consider covering well-established alternative medicine modalities that have already achieved success among 9/11 responders and survivors, including acupuncture, nutrition, massage and herbal detoxification programs

The Survivor Community (SC) – (Survivor Workers, Survivor Residents & Survivor Students)

Survivors and Responders

1. The survivor program is very different from the responder program
    a. A SC participant is required to have a WTC-identified symptom in order to be enrolled in the treatment program
        i. Then they get yearly revisits for monitoring
    b. On the other hand, responders are monitored and then, accordingly, sent for treatment
    c. We want the SC to be monitored in the same way that the RC is

2. We want one list of conditions for the whole 9/11 community, which includes illnesses as they arise in sufficient numbers
    a. Right now the Act is structured so that if a condition is added for responders, then it is added for survivors
    b. We want to make sure that the reverse is also carried out, such that survivor conditions can be added of their own accord, with responders following

Exclusion barriers

1. Treating physicians should have the discretion in the certification of residents, students and area workers who are sick from being exposed to WTC dust and smoke in the geographical area between Houston Street and 14th Street
2. The process for certifying prospective participants must not create a barrier to care

Affected children

1. We want to make sure that special attention is given to children's issues
2. In addition to the respiratory and aero digestive disorders on the list of covered conditions, neurodevelopmental disorders are being treated in the WTC Pediatric Program
    a. These disorders are something specific to children, resulting, for example, when they are exposed to toxic chemicals at a young age or even *in utero*
3. It must be a research priority to address the gaps in our understanding of the mental and environmental health impacts of 9/11 on children and adolescents
    a. Even the City of New York acknowledges this gap.[2]

[2] WTC Medical Working Group of New York City,"2010 Annual Report on 9/11 Health," September 2010, p. 5 http://www.nyc.gov/html/doh/wtc/downloads/pdf/news/2010_mwg_annual_report.pdf.

Community Input

Participants' Program Evaluation

1. There should be a process for participants to evaluate the program
    a. Participants should be given an evaluation survey when they come in for their annual exam
    b. This will provide feedback on how well the program is meeting their needs
    c. These "report card" findings should be included in the quarterly newsletter sent out by the CoEs

2. There should be periodic focus groups to get a barometer reading of how the program is functioning and what needs adjustment

3. There should be grievance procedure for any and all complaints
    a. There currently is none

4. The evaluation process and grievance procedure should be addressed within a larger body that exists to serve the participants' needs (see below)

Community Advisory Council

1. Some in the 9/11 community have been working in partnership with personnel at one of the CoEs to create a Community Advisory Council (CAC) in order to improve the overall experience of participants and to encourage participation through improved hospitality, etc.
    a. This team plans to continue that discussion and develop protocols that can be inserted into the larger process

2. The CAC should be part of the larger process of the Act's mandate to establish a formal mechanism for consulting with and receiving input from responder and survivor representatives (Section 3305)

3. There should be a CAC established at each WTC HP center
    a. Each council should serve the medical care needs of that particular center's participants
    b. Since not all monitoring participants are in the treatment program, the CAC should be comprised of participants who are solely in the monitoring program and those who are in both programs
    a. Each CAC should develop the protocol for the grievance procedure at its CoE

4. There should be a Coalition of WTC HP Community Advisory Councils that would have approximately 2 to 3 representatives from each CAC

5. CBPR would serve as model for the structure and philosophy of the CAC and the Coalition

6. Each CAC would have 1 to 2 representatives on the Steering Committees (see below).

Advisory Committee

- The WTC Health Program Scientific/Technical Advisory Committee (abbreviated in the Act as the "Advisory Committee") and

1. The experts who sit on the Advisory Committee will make decisions of paramount importance to the 9/11 community

2. There must be 9/11 responder and survivor input into the scientific and technical advisor membership of the Advisory Committee

3. The WTC Program Administrator should preside over a transparent process where stakeholders have the right to nominate experts and other representatives and to have meaningful input into the appointment of Advisory Committee members

Adding Covered Conditions

1. The Advisory Committee must operate as a CBPR process which allows the 9/11 Community an opportunity to review all presented evidence used to support or deny petitions for adding new conditions or petitions for changing eligibility requirements

2. We want to make sure that the standard used is such that the scientists are looking at a whole range of studies, including occupational studies, environmental health studies and animal studies
    a. This is in addition to studies of the broad 9/11 community itself

Outreach

1. We know from various 9/11 organizations, including family groups, that as we approach the 10th anniversary more people are coming forward for the first time looking for services
    a. Some organizations are now seeing a different population surfacing than their primary target audience
        i. E.g., media who worked at the various sites, people who live outside the NY metro area, and people who live locally, but are now seeing problems within their family
2. Much of this new population is looking for mental health services, though some are looking for medical services as well
    a. We are concerned that the Act will not meet the needs of these populations
    b. We still consider them part of our 9/11 community, and we want to make sure that their needs are addressed

3. The outreach for the Clinical Centers and Data Centers should utilize programs conducted by trusted community- and labor-based groups with established reach into the affected populations of 9/11 survivors and responders.

"Any nation that does not honor its heroes will not long endure" Abraham Lincoln