The World Trade Center Medical Monitoring and Treatment Program
Purpose of Briefing

• Present Status of the WTC Monitoring and Treatment Program

• Describe a Strategic Plan for a Nationwide WTC Health Care Program
The attacks on the World Trade Center of September 11, 2001 produced the largest acute environmental disaster that ever befell New York City.
What kinds of workers and volunteers were involved in rescue and response efforts?

- Firefighters
- Law enforcement (local, regional, state, and federal)
- Utilities workers (electric, gas, telephone)
- Transportation (Rail, subway, bus, trucking)
- Health care (EMTs, MDs, RNs, coroner, forensic pathologists, mental-health specialists)
- Building trades
Topics for the Briefing

• WTC Program Implementation History
• Overview of Current Program Structure
• Program Status/Accomplishments
• Program Challenges/Requirements
• Strategic Plan for Future Program
Program Definitions

• V1: The first comprehensive health exam provided responders. These were funded primarily through the initial contract

• V2: The second comprehensive exam provided responders. These are funded by the cooperative agreement

• Treatment: This is funded by a supplement to the cooperative agreement.
# WTC Program Implementation

## Monitoring and Treatment Program

<table>
<thead>
<tr>
<th>Date</th>
<th>Awarded</th>
<th>Mechanism</th>
<th>Appropriation</th>
<th>Members</th>
<th>IRB</th>
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<tr>
<td>FY 2002</td>
<td>Mt. Sinai</td>
<td>Contract (Screening, V1)</td>
<td>$12,000,000</td>
<td>12,000</td>
<td>Yes, required by institution for Mt. Sinai and all performance sites.</td>
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<td>FY 2004</td>
<td>Mt. Sinai, FDNY, UMNDJ, Queens, Bellevue, Stonybrook</td>
<td>Cooperative Agreement (Monitoring, V2)</td>
<td>$90,000,000</td>
<td>37,000</td>
<td>Yes, required by institutions of all awardees.</td>
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<td>FY 2006</td>
<td></td>
<td>Supplement (Treatment and Existing Programs)</td>
<td>$75,000,000</td>
<td>TBD</td>
<td>No, agreed it was for medical services and not research.</td>
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</table>
WTC Treatment and Monitoring Program

Mt Sinai DCC
Data Management
- Nat'l Program for Care & Monitoring
- 3rd-Party Payment for Referral
- Phone Center
- Outreach
- Steering committee

FDNY DCC
Data Management
- Nat'l Program for Care & Monitoring
- 3rd-Party Payment for Referral
- Phone Center
- Outreach
- Steering committee

Mt Sinai
- Pharmacy Plan
- Referral Network
- In-house Care
- Social Counseling
- Monitoring Exam
  - Physical
  - Telephone Update
- Outreach
- Third Party Payment

Queens College
- Pharmacy Plan
- Referral Network
- In-house Care
- Social Counseling
- Monitoring Exam
  - Physical
  - Telephone Update
- Outreach
- Third Party Payment

Stony Brook
- Pharmacy Plan
- Referral Network
- In-house Care
- Social Counseling
- Monitoring Exam
  - Physical
  - Telephone Update
- Outreach
- Third Party Payment

UMDNJ
- Pharmacy Plan
- Referral Network
- In-house Care
- Social Counseling
- Monitoring Exam
  - Physical
  - Telephone Update
- Outreach
- Third Party Payment

Bellevue
- Pharmacy Plan
- Referral Network
- In-house Care
- Social Counseling
- Monitoring Exam
  - Physical
  - Telephone Update
- Outreach
- Third Party Payment

<--------Limited Information Sharing-------->
WTC - Registrants in Mt. Sinai Consortium
(Total of 27,324 of which 71% have had examinations)
WTC MMTP - Distribution by Clinic of Number of Responders in Monitoring (36,775 as of 3/31/07)

- FDNY, 14,308
- Mount Sinai, 14,314
- National, 2,894
- Long Island, 2,647
- Queens, 1,183
- UMDNJ, 783
- NYU Bellevue, 646
World Trade Center – National Program
Locations of Responders Who Are Registered (2894*)

* This estimated number includes a few responders from the District of Columbia (12), Puerto Rico (7), Virgin Islands (7), and Canada (12). Locations of 403 current federal responders are not yet known.
WTC MMTP - Number of V1, V2, and V3 Exams Reported by DCCs
(as of 3/31/07)

<table>
<thead>
<tr>
<th></th>
<th>V1</th>
<th>V2</th>
<th>V3</th>
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<tbody>
<tr>
<td>Sinai Cons</td>
<td>19,573</td>
<td>7,626</td>
<td>243</td>
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<tr>
<td>FDNY</td>
<td>14,308</td>
<td>10,392</td>
<td>1,885</td>
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WTC Treatment Program Covered Conditions

New onset or aggravation of pre-existing conditions for which clinical findings suggest onset is related to WTC exposure/injury

Aerodigestive Disorders
Asthma, Chronic Cough Syndrome, Chronic laryngitis, Chronic nasopharyngitis, Lower Respiratory Disorders –Fumes/Vapors, Chronic rhinosinusitis, Gastro-esophageal Reflux Disorder (GERD), Interstitial lung diseases, Reactive Airways Dysfunction Syndrome (RADS), Sleep apnea exacerbated by or related to the above conditions, Upper airway hyper-reactivity, WTC-exacerbated chronic obstructive pulmonary disease (COPD)

Mental Health Conditions
“V codes” (treatments not specifically related to psychiatric disorders, such as marital problems, parenting problems etc.), Acute Stress Disorder, Adjustment Disorder, Anxiety Disorder (not otherwise specified), Depression (not otherwise specified), Dysthymic Disorder, Generalized Anxiety Disorder, Major Depressive Disorder, Panic Disorder, Post Traumatic Stress Disorder (PTSD), Substance Abuse

Musculoskeletal Disorders
Carpal Tunnel Syndrome (CTS), Low back pain, Other musculoskeletal disorders
WTC MMTP - Patients in Treatment for Physical Health and Mental Health as a Portion of the NYC Monitoring Cohort (as of 3/31/07)

Total Cohort: 33,923
Pts-PH (19%): 6,533
Pts-MH (14%): 4,688
Mt Sinai Patients Examined and Referred to Physical Health and Mental Health Treatment from 1/1/07 to 3/31/07

<table>
<thead>
<tr>
<th></th>
<th>Monitored</th>
<th>Pts-PH</th>
<th>Pts-MH</th>
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<tbody>
<tr>
<td>V1</td>
<td></td>
<td></td>
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<td>V2</td>
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<td>V3</td>
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<tr>
<td>Total</td>
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</table>

V1: PH - 51%, MH - 25%;
V2: PH - 44%, MH - 26%;
V3: PH - 39%, MH - 26%;
Total: PH - 47%, MH - 26%
Current Program Challenges

• Budget and Exams: Expected Versus Actual
• Cost Tracking for Current and Future Needs
• Disease Tracking
• Clinic Capacity
• Clinic Space
• Engagement of Medical Center Resources
• 8 Health Care Plans with loose coordination
Current National Program Challenges

- FOH – no monitoring
- AOEC with Red Cross and Mt Sinai – limited individual data/fragmented system
- Mt Sinai DCC – limited # of clinics
- FDNY – retiree relocation
- No centralized data system and medical management
Future Program Requirements

- Billing linked to CPT, ICD9 or HIPAA coding
- Ombudsman
- Appeals procedure
- Medical review/case management
- Cost analysis/payment schedules
- Centralized Database
- Compliant with HIPAA Transaction Rules
- Satisfy Medicare Standards for a Health Care Plan
Strategic Plan for a Nationwide WTC Responder Health Care Program

Excellence in Care, Coordination and Analysis for WTC Responder Cohort Members
Considerations for a Nationwide WTC Responder Health Care Program

• States regulate health care delivery
• Medicare approves health insurance plans within a State. These approved plans solicit subscribers for their health care program. In most States there are too few WTC responders to make it cost effective for a health insurance plan to develop a program
• Consolidation/analysis of certain data is necessary
• Disease/Case Management is essential for ensuring WTC Responders receive state-of-the-art health care
Nationwide WTC Responder Health Care Program

Advice

Outreach

WTC Responder Health Care Program

Federal Science Funding For Investigator Initiated Projects

Care:
• Providers
  • Centers of Excellence
  • Certified for Monitoring
  • Certified for Treatment
• Medical Management
• Data Collection/Transfer
• Continuous Quality Improvement
• Information Services
• Standard Health Insurance Reporting

Coordination:
• Component Coordination
• Member Services
• Health Management
• Awardees Steering Committee
• Centers of Excellence

Data Collection & Analysis:
• Platform Development, Utilization & Tool Design
• Quality Assurance/Confidentiality
• Disease Surveillance
• Responder Health Analyses
• Platform for Research Projects
WTC Responder Health Care Program

• Ensure nationwide, uniform, high quality care for WTC Responder Cohort Members
• Administer the contracts and/or grants
• Facilitate communication and exchange of information
• Evaluate and report accomplishments of the program
• Provide direction for studies on the cohort
• Review progress and approve funding
• Determine if requests for change of scope or re-budgeting are appropriate for program goals
• Ensure study results inform clinical care
Advice

• Federal Advisory Committee
• Health and Human Services
  – Office of the Secretary
  – Centers for Disease Control
  – NIOSH
  – Agency for Toxic Substances and Disease Registry
  – National Institutes of Health
Program Outreach

- Awardees WTC Steering Committee
- World Trade Center Advocacy Groups
- WTC Member Groups such as Local Trade and Government Unions
- Community-based Organizations
- Professional Associations/Societies
- WTC Credentialed Providers
Care

- **Provider Network**
  - Centers of Excellence: Clinics in the New York City Metro Area
  - Credentialed/Certified Providers
    - Treatment
    - Monitoring

- **Data Collection and Transmission**
  - Monitoring
  - Treatment

- **Management in Accordance with WTC Program**
  - Pre-certification, Utilization, Case Management and Review, Quality Improvement, Compliance, Appeals and Grievances, Health Insurance Data Management, Pharmacy Benefit Management, Provider Relations
  - Claims Processing/Payments
    - Certified WTC Monitoring Exams
  - Member Services
Coordination

• Component Coordination
  • Coordination/Leadership of Centers of Excellence for
    • Health Monitoring Protocol Development & Re-evaluation
    • Review of Covered Conditions
    • Treatment Protocol Development & Re-evaluation
    • Pharmacy Formulary Development & Re-evaluation
  • Collaboration/Coordination of Cross Component Activities
  • Advice on Study Design & Scientific Publications
  • Support Awardees Steering Committee

• Member Services
  • Health Communications
    • Health Information Content Development and Dissemination
    • Publication of Health Care Communications for Patients, Providers, Government & Media
  • Member Eligibility/800 Information Center/Member Outreach/Retention

• Health Management
  • Special Member/Physician Needs such as Translation Support, Low Literacy Support & Transportation Assistance
  • Single Point of Contact for the WTC Program/Information Services

• Awardees WTC Steering Committee
  • Advise Awardees on Member Issues
  • Facilitate Member Participation in Programs

• Centers of Excellence
  • Providers
  • Program Support
Data Collection & Analysis

• Platform and Tool Design for Responder Data
  • Development, Implementation, and Utilization of a WTC Responder Data Platform
  • Development of Data Collection Tools
  • Ensure FDNY and Non-FDNY Data Tables are Complete and Compatible

• Quality Assurance/ Confidentiality
  • Protection of Patient Confidentiality, Human Subjects Review Regulations, and Data File Access
  • Quality Assurance Analysis to inform Continuous Quality Improvement Process
  • Certification of the Monitoring Exam for Payment
  • Data on Occupations, Exposures, Clinical Findings, etc
  • Perform Standard Descriptive Reporting, Special Case Analysis, and Quality Assurance Evaluations
  • Data for Communication Products

• Disease Surveillance

• Responder Health Analyses/Study Design
  • Longitudinal Analysis of Incidence and Outcome Data on Respiratory, Mental Health, Outcomes, Treatment Effects and Fatalities
  • Other Analyses
  • Publication of Results in Peer Reviewed Literature

• Platform for Peer Reviewed, Funded Collaborative Research Projects
Federal Science Funding for Investigator Initiated Projects

• Lead the development of requests for applications that are consistent with the priorities established by the WTC Program Office

• Provide resources for studies of the responder cohort

• Administer awarded studies
Related Resources

• WTC Resident, Non-Qualified Responders and Office Re-Occupants Health Registry

  • Patient Confidentiality, Human Subjects Review Regulations, and Data File Access will be Protected
  • Development of a Short Data Collection Instrument Tools
  • Publication of Reported Incidence Data
  • Platform for Peer Reviewed Research Projects
Cost Considerations and Projections for a Nationwide World Trade Center Responder Health Care Program
Cost Estimate Considerations for a Nationwide WTC Responder Health Care Program

Health Care
- More responders are still registering.
- Responders needing treatment are increasing, many with more than one health problem.
- Illness intensity of responders is increasing (greater treatment cost).
- Hospital costs are uncertain but potentially high.
- Annualized monitoring exams are medically indicated and cost effective for early illness detection.
- Support needs such as outreach, retention, social work, and language translation services require additional funds.

Coordination and Analysis
- Coordination and analysis are needed to evaluate health outcomes and inform future program directions.

Overall WTC Responder Health Care Program
- To ensure success, resources are needed long-term with funding on a periodic basis such as five-year intervals.
- An initial 5-year budget plan can be based on an estimate of current cost for year 1, reaching probable costs by year 3, and inflation of 4% thereafter.
Cost Estimate Scenarios for the WTC Responder Health Care Program

- **Current** - what the program is experiencing now

- **Probable** - what the program is likely to experience over the next two years based on growth in (1) number of registered responders (more registrations are occurring now than in any prior year except the first year after 9/11), (2) percent of responders that are needing treatment (based on information from January to March 2007), and (3) intensity of illnesses (it is costing more to treat ill responders)

- **Possible** - what the program might experience over the next two years if even more of the possible eligible responders register, the percentage of the cohort needing treatment is nearer to the high-end of the estimate, and illness intensity continues to increase.
## Annual Cost Estimate (in millions)

<table>
<thead>
<tr>
<th>Elements of Annual Cost Estimate</th>
<th>Current</th>
<th>$ in M</th>
<th>Probable</th>
<th>$ in M</th>
<th>Possible</th>
<th>$ in M</th>
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<tbody>
<tr>
<td>Number of people in monitoring (baseline exams)</td>
<td>37,000</td>
<td>55,000</td>
<td>65,000</td>
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<tr>
<td>Average treatment cost per responder</td>
<td>$8,000</td>
<td>$9,200</td>
<td>$10,500</td>
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<td>Percent of responders with aerodigestive conditions</td>
<td>19%</td>
<td>$56</td>
<td>33%</td>
<td>$167</td>
<td>47%</td>
<td>$321</td>
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<tr>
<td>Percent of responders with psychological conditions</td>
<td>14%</td>
<td>$41</td>
<td>20%</td>
<td>$101</td>
<td>26%</td>
<td>$177</td>
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<tr>
<td>Percent of responders with musculoskeletal conditions</td>
<td>1%</td>
<td>$3</td>
<td>1%</td>
<td>$5</td>
<td>1%</td>
<td>$7</td>
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<tr>
<td>Data management cost per responder</td>
<td>$500</td>
<td>$19</td>
<td>$550</td>
<td>$30</td>
<td>$600</td>
<td>$39</td>
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<tr>
<td>Annual monitoring exam cost per responder</td>
<td>$1,150</td>
<td>$43</td>
<td>$1,250</td>
<td>$69</td>
<td>$1,350</td>
<td>$88</td>
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<td>Hospitalization cost for 1% of responders</td>
<td>$10,000</td>
<td>$4</td>
<td>$11,000</td>
<td>$6</td>
<td>$12,000</td>
<td>$8</td>
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<td>Support needs cost per responder</td>
<td>$320</td>
<td>$12</td>
<td>$350</td>
<td>$19</td>
<td>$380</td>
<td>$25</td>
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<tr>
<td>Subtotal - Direct Health Care</td>
<td>$177</td>
<td>$398</td>
<td>664</td>
<td></td>
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<tr>
<td>Administrative Costs for all health care</td>
<td>5%</td>
<td>$9</td>
<td>5%</td>
<td>$20</td>
<td>5%</td>
<td>$33</td>
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<td>Health Care</td>
<td><strong>$186</strong></td>
<td><strong>$417</strong></td>
<td>698</td>
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<td>Program Coordination</td>
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<td>Program Analysis</td>
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<td>Federal Government Operations &amp; Reporting</td>
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<tr>
<td>Total WTC Responder Health Care Program</td>
<td><strong>$195</strong></td>
<td><strong>$428</strong></td>
<td><strong>$712</strong></td>
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</table>
Forward Cost Considerations

- Costs are based on point estimates from limited data that have substantial variability.
- Fees for services must include institution overhead rates, so the costs will be higher by 20% - 30%.
- Academic Centers will need a base funding level to counteract the uncertainty of a fee-for-service approach so that a known amount of funding for facilities and staff can be ensured for business planning.
- Support needs such as outreach, retention, social work, and translation services are influenced by the demographics of the responders.
- Administrative Costs for the overall program need to be verified.
- Coordination and Analysis costs include overhead charges for institutions, so direct costs would be about 70% of those amounts.
- Coordination and Analysis costs could be higher in order to address a wider scope of activities that are determined to be important for the responders.
- Federal Government operations and reporting costs are to support staff and related costs of program planning, implementation, and evaluation, as well as stewardship of grants and contracts.
Discussion