World Trade Center Health Program
(WTCHP) Research

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Presentation Outline

• Research Program Overview
• Research Evaluation
  – Steps to Implementation
  – Tools—Publication Database, Research Compendium, Specialty Workshops/Grantee Meetings
• Portfolio Summary
  – Summary of WTC Health Registry Scientific Outputs
  – Summary of Portfolio Scientific Outputs (Individual PI Projects)
  – Feasibility of Children’s Cohort Expansion
WTC Research Program Overview

Goal
Investigate the physical and mental health impact/burden on the WTC Population

Agenda/Scope
• Investigate new links between 9/11 exposures and adverse health effects
• Further characterize WTC-related health effects
• Examine the health & development of children exposed on 9/11
• Investigate and improve disaster-related health-services

Research Impact
Utilize research findings to improve treatment for responders and survivors and inform the Research Agenda
Research Evaluation

• **Collect and Organize Data**
  – Publication Database
  – Research Compendium
  – Grantee Meetings and Specialty Workshops—presentations and transcripts

• **Synthesis of Data**
  – Publishable document or technical report outlining key research findings, gaps, and recommendations

• **Results**
  – Modify Research Agenda
  – Improve Care (diagnosis and treatment)
  – Communicate findings to clinicians, researchers, and the public
WTC Research Publication Database

• 1,363 WTC Research Publications (2001-Present)
  – Publications cited by the NYC Mayor’s Working Group
  – Publications from the 2016 AJIM “Special Issue: Health Effects of 911: Fifteen-Year Reports”
  – Conference abstracts

• All Publications Listed in the WTC Research Compendium
  – Data Center Publications: 2002 – Present (FDNY, NYC H+H, and Mount Sinai)
  – WTC Health Registry Publications: 2006 – Present
  – WTC Research Program Publications: 2011 – Present
WTC Research Compendium

- **Provides Necessary Information**
  - Assess future research directions
  - Assess the impact of current studies
  - Identify research gaps
  - Conduct structured reviews

- **Key Content Areas**
  - Publications (pre- and post- Zadroga)
  - Recommendations to the WTCHP
  - Listing of all projects funded
Research Compendium
2002 – 2009 (Pre-Zadroga)

• Medical Programs/Data Centers Established
  – 209 publications to-date (FDNY, Mount Sinai, and NYC H+H)

• WTC Health Registry Established
  – 83 publications to-date

• NYC Mayor’s Working Group (2007 – 2011)
  – Recommendation categories—research and evaluation, education, and funding
Research Compendium
2010 – Present

• Zadroga Act Passed by Congress (2011)
  – Establishes Federal Funding for Research and Registry

• Initiation and Development of the WTC Research Program
  – Research Awards To-Date
    • Research Contracts (8)
    • Research Cooperative Agreements (58)
    • Continuation of the WTC Health Registry
Specialty Workshops

• Workshops Conducted
  – Respiratory Disease
  – Mental Health Respiratory Disease Comorbidity

• Questions
  – What is known based on research results?
  – What has been the impact on treatment?
  – What are the current research gaps?
  – What are the recommended future research directions?

• Product(s)
  – Meeting transcript and Research Recommendations
Specialty Workshops Planned

• June 2018
  – WTC Research Needs: A Clinical Perspective (CCE Directors)

• November 2018
  – WTC Cancer Research

• June 2019
  – WTC Children’s Research

• November 2019
  – WTC Emerging Conditions
WTC Health Registry

- **Voluntary enrollment of responders and residents**  
  \( N = 71,437 \)
  - 30,665 responders
  - 40,772 residents (excl. responders)
  - 3,251 <18 years old on 9/11
  - ~17% enrollment of eligible pop.

- **Data gathering for research**
  - Mortality, cancer, and clinical data
  - Periodic surveys (“waves”) every 3 to 4 years
  - In-depth/clinical studies of selected subgroups

**Scientific Outputs 2004 – 2017**

- **External Research PhD and Master’s Theses**
  - 7
- **Technical Reports and Clinical Guidelines, and Public Use...**
  - 18
- **PhD and Master’s Theses**
  - 23
- **External Research Publications**
  - 32
- **Publications**
  - 98
- **Scientific Presentations**
  - 205
- **Total**
  - 390
Awarded Projects \((N=66)\) and Publications by Focus Area (2011–2018)

- **Respiratory** ($29.4M): 
  - Publications: 28
  - Projects: 17

- **Mental Health** ($20.4M): 
  - Publications: 24
  - Projects: 15

- **Cancer** ($15M): 
  - Publications: 12
  - Projects: 6

- **WTC Youth** ($13.1M): 
  - Publications: 8
  - Projects: 6

- **Emerging Conditions** ($6.9M): 
  - Publications: 9
  - Projects: 5

- **Cardiovascular Disease** ($7.1M): 
  - Publications: 5
  - Projects: 5

Excludes WTC Health Registry projects.
WTC Children’s Cohort Expansion

• **Assess the feasibility of expanding the Children’s Cohort**
  – Determine the availability of NYC Department of Education (DOE) school directory information
  – Develop a protocol for feasibility assessment
  – Develop the required public notification communication

• **Potential Benefits**
  – Evaluation of Health and Educational Outcomes
  – Expansion of non-WTC-Exposed Comparison Group
2018 Research Calendar

March - April
• Progress Reports for all Current Projects (March 1)
• Scientific Peer Review of 2018 Study Proposals (April 11 – 12)

June - July
• Spring/Summer WTC Research Grantee Meeting (June 13 – 14)
• Award Notices for the selected 2018 studies (early July)

November - December
• Letter of Intent (LOI) for 2019 research applications (due November 1)
• Autumn/ Winter WTC Research Grantee Meeting (November 14 – 15)
• 2018 WTC research applications (due December 4)
WTCHP Research Portfolio Information

• Research Web site:
  – https://wwwn.cdc.gov/ResearchGateway

• Research Projects:

• New Research FOA:

• WTC Health Registry:
  – http://www1.nyc.gov/site/911health/index.page
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Questions