#### **WORLD TRADE CENTER**

## HEALTH PROGRAM



Shanksville



**New York City** 



Pentagon

# 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**

#### <u>Goal</u>

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

#### Agenda/Scope

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

#### **Research Impact**

Utilize research findings to <u>improve treatment</u> for responders and survivors and <u>inform</u> 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

## **Summary of WTC Health Program** Research A draft document made available by NIOSH for the purposes of review and comment **NIOSH Research Compendium** W. Allen Robison, PhD Dori Reissman, MD Alan Katruska, BPhil Stephen Cox, MLIS Max Lum, EdD, MPA Robert Daniels, PhD Larry Rhodes, MBA



## 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)

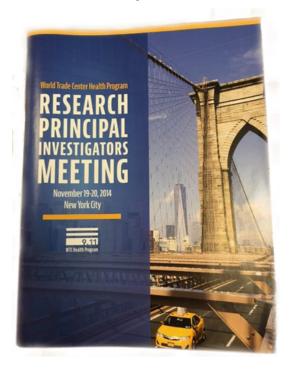
Meeting transcript and Research Recommendations





## **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

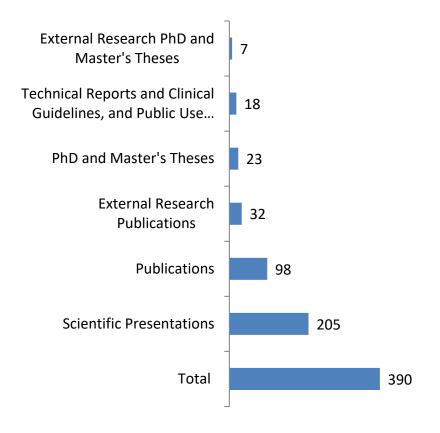




#### **WTC Health Registry**

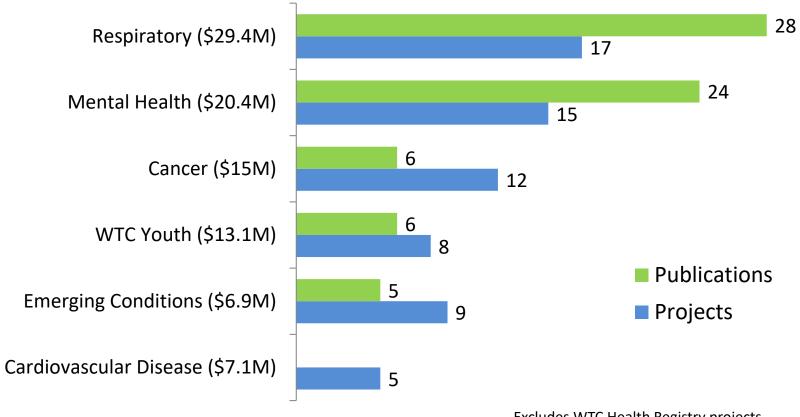
- Voluntary enrollment of responders and residents (*N*=71,437)
  - 30,665 responders
  - 40,772 residents (excl. responders)
  - 3,251 <18 years old on 9/11</li>
  - ~17% enrollment of eligible pop.
- Data gathering for research
  - Mortality, cancer, and clinical data
  - Periodic surveys ("waves") every 3 to 4 years
  - In-depth/clinical studies of selected subgroups

#### Scientific Outputs 2004 – 2017





#### Awarded Projects (N=66) and Publications by Focus Area (2011–2018)





## WTC Children's Cohort Expansion

- Assess the <u>feasibility</u> 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:
  - https://wwwn.cdc.gov/ResearchGateway/ResearchProjects
- New Research FOA:
  - https://grants.nih.gov/grants/guide/pa-files/PAR-16-098.html
- WTC Health Registry:
  - http://www1.nyc.gov/site/911health/index.page



#### **WORLD TRADE CENTER**

## HEALTH PROGRAM

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## Questions

