



Shanksville



New York City



Pentagon

## World Trade Center Health Program Research Activity Update

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## Presentation Outline

- **WTC Research Program Overview**
  - Mission and Scope
  - Program Statistics
  - Research Projects and Publications
  - Summary of Research Findings
- **Overview of WTC Research Program Operational Overview**
  - Primary Goals and Activities
  - Bi-Annual Research Meetings
  - Special Emphasis Workshops
- **WTC Research Resources for the STAC**
  - WTC Publication Database
  - WTC Research Compendium

## WTC Research Program Overview

### Research Mission

To investigate health impacts (and disability) arising from the 9/11 attacks and to optimize WTC responder and survivor care.

### Research Agenda/Scope

- Conduct research to inform areas where there is treatment and/or diagnostic uncertainty.
- 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.

## WTC Research at a Glance

### Funded Research

(WTC research solicited annually on a 5-yr. cycle)

- **77** WTC research projects funded between 2011-2019
- **80** WTC Health Registry research projects and surveys

### WTC Research Publications

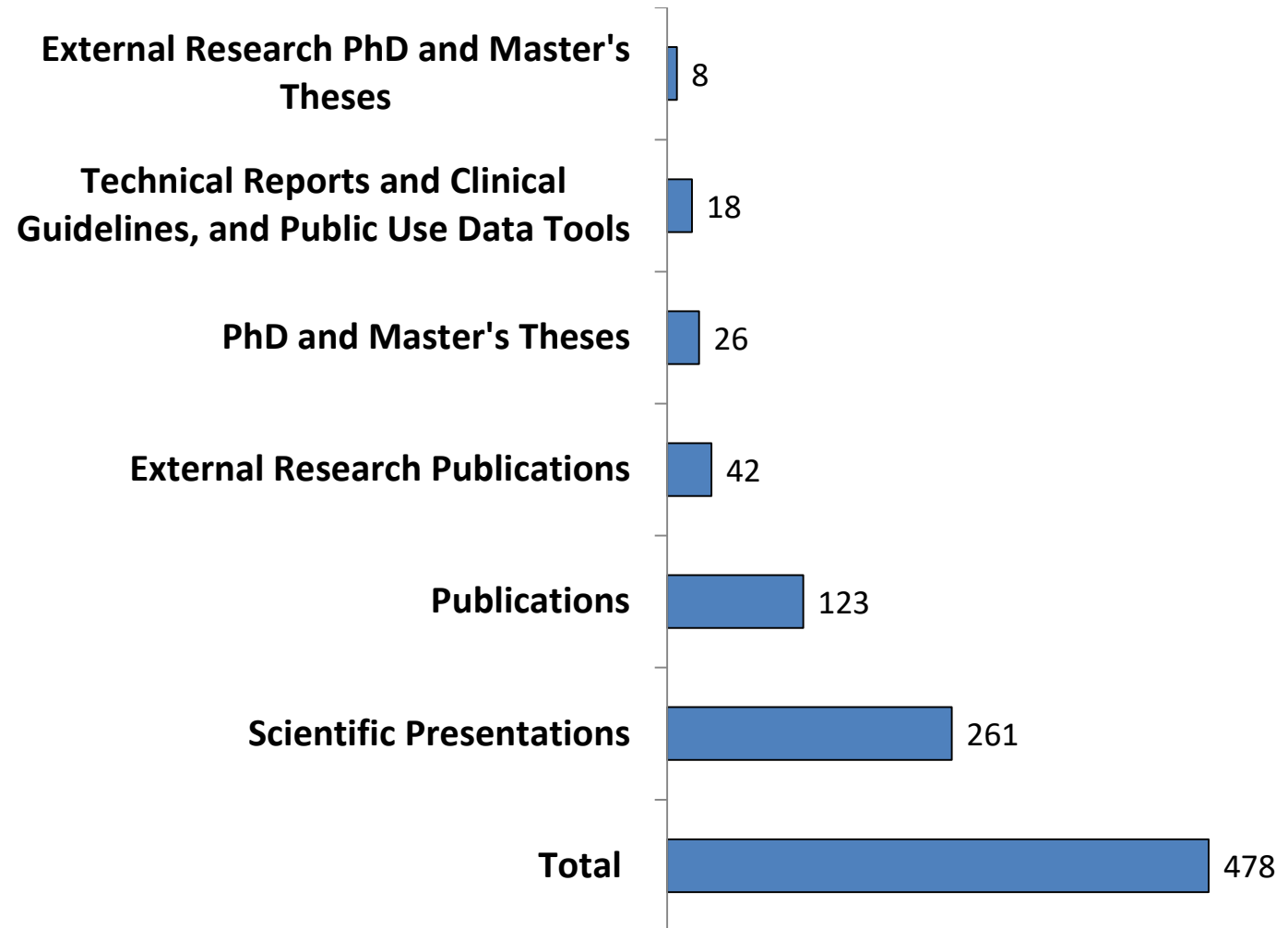
(Funded by CDC/NIOSH)

- **119:** WTC Research Projects (2011-2019)
- **107:** WTC Health Registry (2006-2019)
- **233:** Data Centers (2002 – 2019)
- **459:** Total Publications

## WTC Health Registry

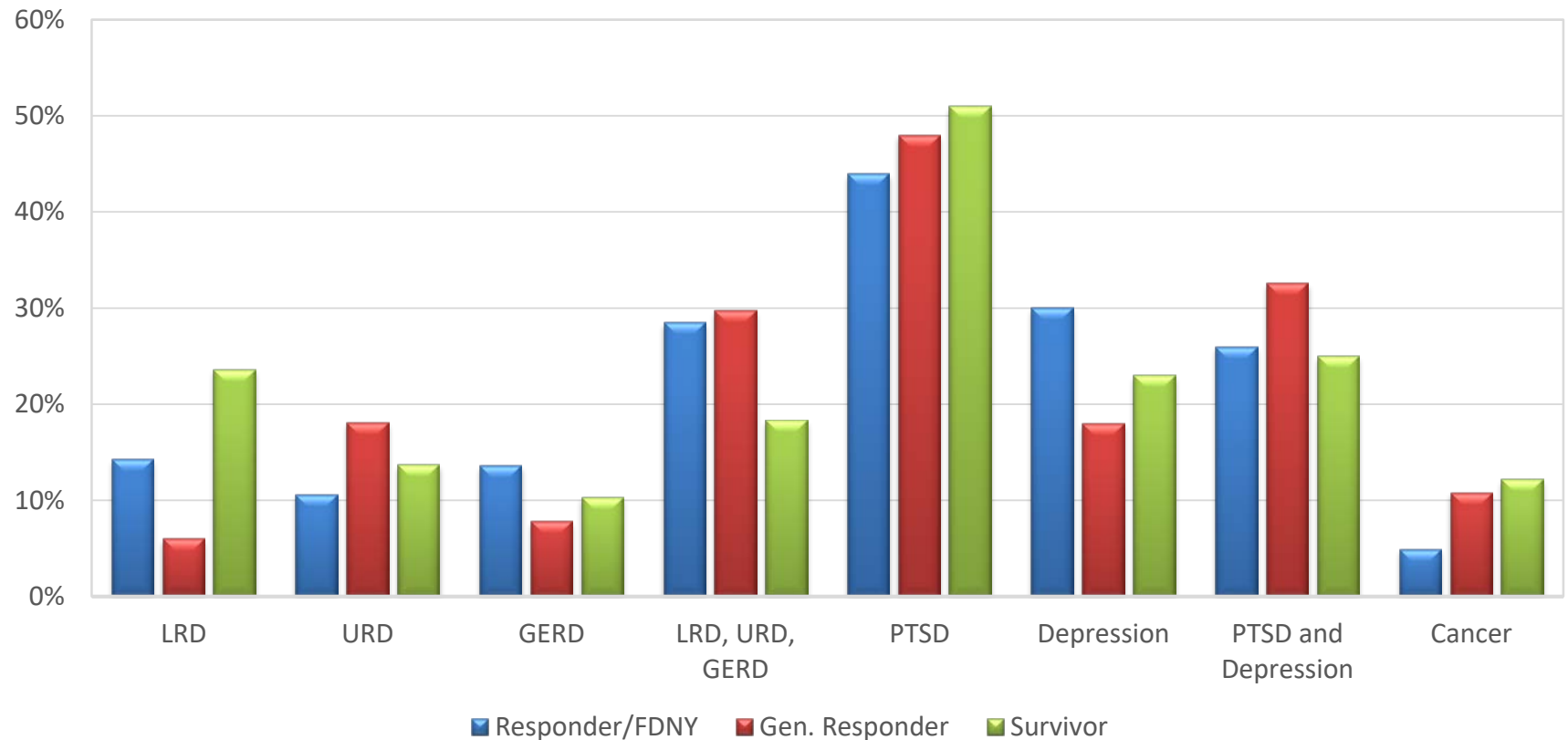
- **Voluntary enrollment of responders and residents (N=71,426)**
  - 30,662 responders
  - 40,764 (incl. residents, people working in buildings in lower Manhattan & people in transit/on the street)
  - 3,251 <18 years old on 9/11
  - ~17% enrollment of eligible pop.
  
- **Data gathering for research**
  - Mortality, cancer, and clinical data
  - Periodic surveys (“waves”) every 3 to 4 years
  - In-depth/clinical studies of selected subgroups

## Scientific Outputs 2004 – June 2019



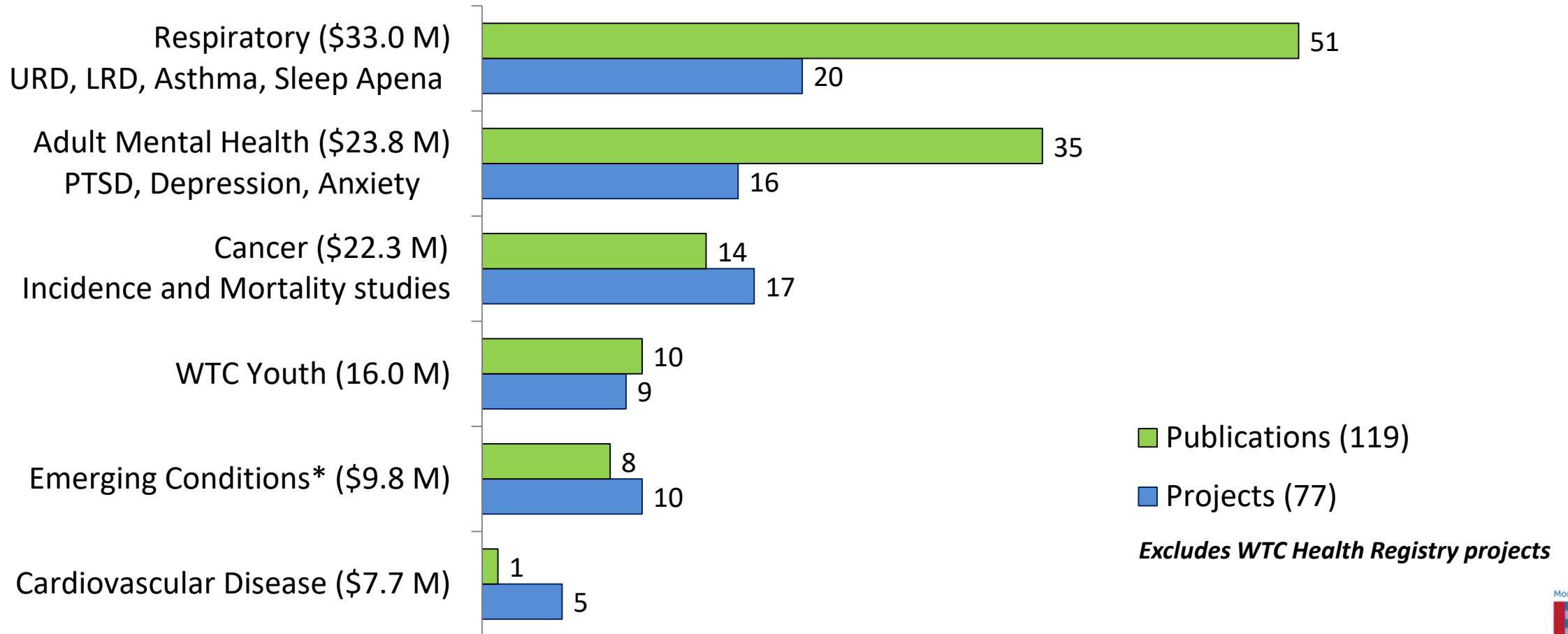
## Overview of Certified Conditions

- Lower Respiratory Disease (LRD)
- Upper Respiratory Disease (URD)
- LRD, URD, GERD  
*(Individuals with all three conditions)*
- PTSD and Depression  
*(Individuals with both conditions)*
- Cancer



More information on covered conditions: <https://www.cdc.gov/wtc/conditions.html>

## Awarded Projects and Publications by Focus Area (2011–2019)



\*Emerging Conditions represents a variety of topics, including Autoimmune Disease, Cognitive Aging, etc.

## A Snapshot of Respiratory Disease Research Findings

- **High post-exposure health burden and persistence of aerodigestive conditions.**
  - Asthma: [Brackbill \(2009\)](#)
  - URD and LRD: [Yip \(2016a\)](#)
  - Persistence of LRS accompanied by mental health conditions: [Friedman \(2016\)](#)
- **High comorbidity commonly reported.**
  - URD, LRD, complicated by GERD: [Prezant \(2002\)](#)
  - Comorbid GERD, Asthma, PTSD: [Li \(2011\)](#)
  - A substantial proportion of FDNY responders have been diagnosed with OAD, CRS, and GERD; 25% have two or more of these conditions: [Yip \(2016b\)](#)
- **Poor control of 9/11-related asthma among adults.**
  - High rates (67%) of poor asthma control among rescue/recovery workers and community members: [Jordan \(2015\)](#)
  - Improving WTC-related asthma outcomes will require multifactorial approaches, e.g., supporting adherence to controller medications: [Rojano \(2018\)](#)
- **WTC dust exposure & changes in pulmonary function.**
  - Reduction of pulmonary function among FDNY Responders: [Banauch \(2003 and 2006\)](#)
  - Predictors of Asthma/COPD: [Singh \(2018\)](#)
  - FEV 1 Decline: [Zeig-Owens \(2018\)](#)
  - TX of Lung Function Decline (Started): [Weiden \(2019\)](#)



## A Snapshot of Mental Health Research Findings

- **High post-exposure burden and persistence**
  - Significant PTSD prevalence among survivors: [DiGrande \(2008\)](#) and [\(2010\)](#)
  - Significant Depression and PTSD: [Caramanica \(2014\)](#)
  - *A sizable PTSD subgroup needs continued treatment:* [Bromet \(2016\)](#)
- **High comorbidity of mental and physical health conditions commonly reported.**
  - Asthma and PTSD comorbidity: [Brackbill \(2009\)](#)
  - Lower respiratory symptoms & PTSD: [Friedman \(2016\)](#)
- **Identification of PTSD symptom trajectories**
  - PTSD symptom Trajectories: [Feder \(2016\)](#)
  - Course of PTSD Symptoms: [Maslow \(2015\)](#)
- **Future Research Directions/Needs**
  - PTSD and Risk for MI and Stroke: [Remch \(2018\)](#)
  - CVD and PTSD: [Jordan \(2013\)](#)
  - Persistent unmet mental health care needs: [Ghuman \(2014\)](#)
  - Examination of the use of Telemedicine for mental health treatment

## WTC Cancers

FDNY  
Responders

- Prostate
- Thyroid
- Non-Hodgkin Lymphoma
- Melanoma
- [Zeig-Owens](#) (2011)

WTC Health  
Registry

- Prostate
- Thyroid
- Non-Hodgkin Lymphoma  
(Civilian Survivors)
- Female Breast Cancer  
(Civilian Survivors)
- Multiple Myeloma
- Li ([2012](#) & [2016](#))

General  
Responders

- Prostate
- Thyroid
- All Cancers Combined
- [Solan](#) (2013)

## Emerging Potential WTC Conditions and Initiatives

- **Assessing the Potential Impact** of Cognitive Aging and Impairment
  - PTSD predictive of cognitive impairment (CI) 14 years post-9/11: *Clouston* ([2016](#) & [2019](#))
  - Cognitive reserve and memory loss: *Seil* ([2019](#))
  - Expert Workshop scheduled for October 2019
- **Assessing Autoimmune Disorders**
  - WTC Health Registry Autoimmune Disease Survey—2019 anticipated completion
  - WTC General Responder Cohort autoimmune surveillance report—anticipated completion 2019
- **Completion of Feasibility:** WTC Children’s Cohort Expansion
  - Initial data received from the New York Department of Education and are being assessed by NYC DOH

## Key Research Program Operational Goals

Constant collection, review, assessment, and synthesis of WTC research information

- Assess and maximize the research impact/benefit to enrollees/patients
- Identify knowledge gaps and research needs
- Identify emerging conditions
- Inform funding decisions

## Key Research Activities

- Collect and catalogue WTC research publications
- Solicit research recommendations from internal and external stakeholders
- Conduct systematic review(s) of WTC research
  - Type of studies conducted
  - Impact on clinical practice
  - Identification of gaps and needs (recommendations from stakeholders)
  - Assess the overall success of research projects—are they meeting stated goals?
- Synthesize and organize collected information/recommendations
  - Coordinate discussions to determine the most effective scope for research solicitations

## Bi-Annual Research Meetings

- **Presentations of Published Research**
  - What are the key findings?
  - What are key research gaps?
  - What is the impact of research on treatment?
  - What are the recommended future research directions?
- **Specialty Sessions—Research Review/Recommendations**
  - Respiratory disease
  - Mental health/respiratory disease comorbidity
- **Product(s)**
  - Meeting transcript and research recommendations

## WTC Research Special Emphasis Workshops

- **Purpose/Goal:** To ensure that the best up-to-date care is provided to the WTC Health Program enrollees and patients, the WTC leadership will invite national and internal experts to review and discuss selected (targeted) research and clinical practice innovations with WTC researchers, clinicians, and leadership staff.
- **Communication:** Documentation of the proceedings and recommendations will be disseminated to scientists and the public through publications, position papers, and science blogs.

### 2019 Workshops

- *Cognitive Aging and Impairment in World Trade Center Affected Populations*
  - **Objective:** Determine if there is currently an increased risk of cognitive impairment among the WTC population and, if so, what can be done to mitigate risk.
- *Research and surveillance of World Trade Center health conditions: Exploring new data sources and new methods*
  - **Objective:** To discuss ways to more efficiently obtain, match, analyze, and incorporate administrative and other digital data into both research and surveillance goals, as well as to perform effective program evaluation.

## 2019 Research Calendar

### October - December

- Cognitive Aging Workshop (Washington DC, October 29 – 30)
- Autumn/Winter WTC Research Meeting (November 13)
- 2020 WTC research applications (due December 4)
- Data Linkage Workshop (NYC, December 5-6)
- Organize research solicitation planning for the 2021 5-year cycle (late December)



## WTC Health Program Resource Documents

- James Zadroga 9/11 Health and Compensation Act (2010) and Reauthorization Act (2015)
  - <https://www.cdc.gov/wtc/laws.html>
- WTC Health Program Statistics
  - <https://www.cdc.gov/wtc/ataglance.html>
- WTC Health Program List of Covered Conditions
  - <https://www.cdc.gov/wtc/conditions.html>

## WTC Health Program Resource Documents

- WTC Health Registry
  - <http://www1.nyc.gov/site/911health/index.page>
- WTC Research Documents
  - <https://stacks.cdc.gov/view/cdc/70289>
  - <https://wwwn.cdc.gov/ResearchGateway/Publications>
- WTC Research Funding Announcement
  - <https://grants.nih.gov/grants/guide/pa-files/PAR-16-098.html>
- WTC Health Program Continuing Education
  - <https://www.cdc.gov/wtc/training.html>
- WTC R2Care Conference
  - <https://wwwn.cdc.gov/ResearchGateway/R2C>

## STAC FTP Site Reference Documents/Databases

- WTC Research Publication Database
  - Research publications, agency reports, and technical documents
- WTC June 2019 Research Conference Books
  - Research project updates and scientific presentations
- Recent WTC Publications
  - Abstracts of publications from WTC research projects

## Abbreviations

Obstructive Airway Disease (**OAD**)

Obstructive Sleep Apnea (**OSA**)

Chronic Rhinosinusitis (**CRS**)

Upper Respiratory Tract Disease  
(**URD**)

Lower Respiratory Tract Disease  
(**LRD**)

Lower Respiratory Symptoms (**LRS**)

Cardiovascular Disease (**CVD**)

Post-Traumatic Stress Disorder  
(**PTSD**)

Gastroesophageal Reflux Disease  
(**GERD**)

Reactive (lower) Airways  
Dysfunction Syndrome (**RADS**)

Chronic Obstructive Pulmonary  
Disease (**COPD**)

Forced Expiratory Volume in the  
first second (**FEV1**)

Medical shorthand for treatment  
(**TX**)

## Key Contributing Staff

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