



Setting the Stage for Partnerships

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Third Roundtable Meeting – “Working Better Together”

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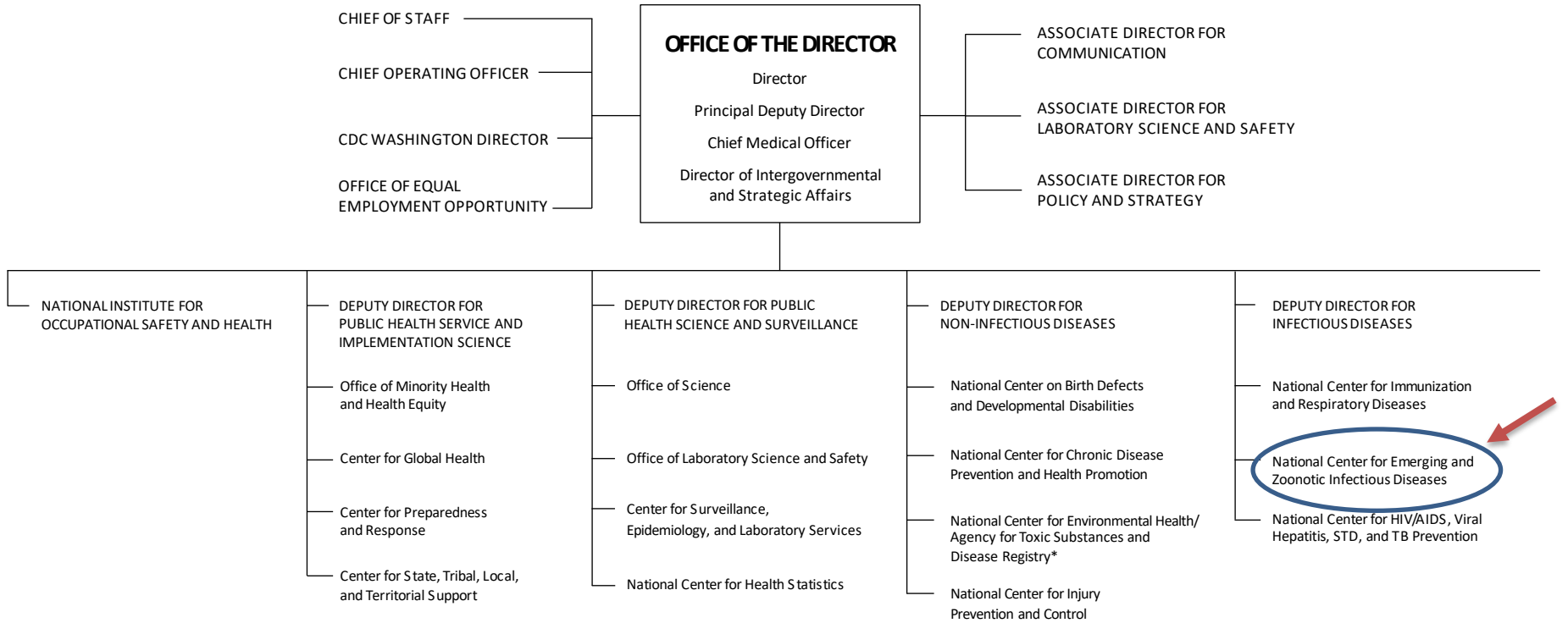
Centers for Disease Control and Prevention

- CDC is the nation's leading science-based, data-driven, service organization that protects the public's health
- Mission –
“We work 24/7 to protect the safety, health, and security of America from threats here and around the world”



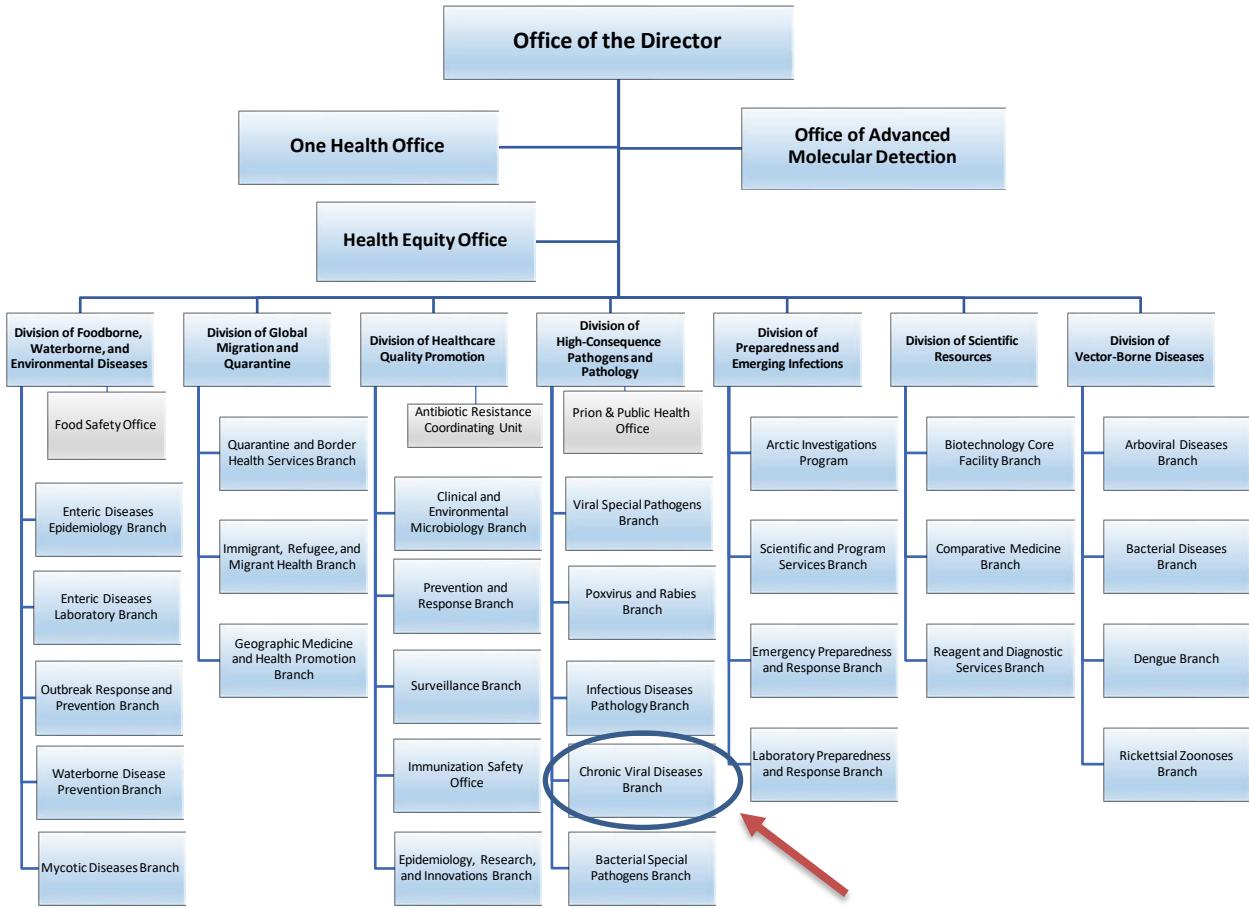
PROTECTING AMERICA'S SAFETY, HEALTH, AND SECURITY

DEPARTMENT OF HEALTH AND HUMAN SERVICES CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)



* ATSDR is an OPDIV within DHHS but is managed by a common director's office.





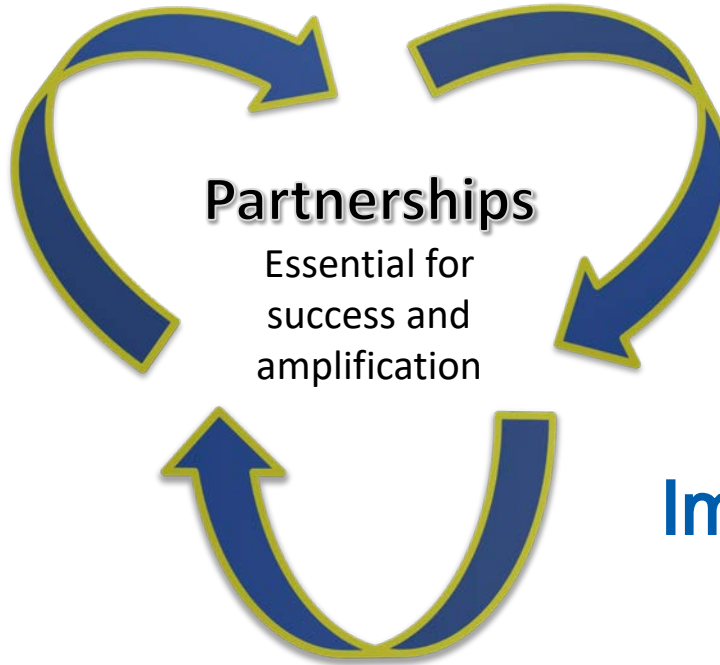
Public Health Approach

Planning

Surveillance/Epidemiology

- How big is the problem?
- Who is affected
- What are risk factors

Needs Assessment



Effectiveness/Impact

- Are interventions working

Sustainability

- Resources sufficient to continue

Efficiency/Relevance

Intervention

- Education and Awareness
- Access to health care
- Prevention and mitigation methods

Research

- Refine understanding of problem
- Identify interventions

Evaluation

Implementation

CDC's ME/CFS Activities – Planning (Surveillance/Epidemiology)

- 1989 – 1994: Physician Surveillance of CFS (1988 case definition)
- 1997 – 2003: Population-based case control studies (1994 case definition)
- 2004 – 2010: Population-based case control study, longitudinal (1994 case definition)
- 2012 – 2020: Multisite Clinical Assessment of ME/CFS – ME/CFS expert clinics
- 2016, 2018, 2020: Behavioral Risk Factor Surveillance System – self-reported diagnosis
- 2018 – present: National Association of School Nurses – school-based surveillance
- 2020 – present: EIP project to describe recent onset ME/CFS

CDC's ME/CFS Activities – Planning (Needs Assessment)

- Surveys (Porter-Novelli and DocStyles) and Focus Groups
- Roundtable meetings
 - 2016: CDC Website and IOM Report
 - 2018: Patient and Provider Toolkit
- CFSAC and Interagency ME/CFS Working Group

CDC's ME/CFS Activities – Implementation (Intervention)

- Provider outreach
 - 2001-2003: Train-the-Trainer
 - 2000-2006: Booths at Professional Conferences
 - 2005-2011: Grand Rounds at Medical Schools
 - 2016: CDC Public Health Grand Rounds
 - 2005-present: CMEs – online at CDC website and Medscape
 - 2012-present: Standardized Patient Modules for Medical Education
- Public education
 - 2007: CFS Public Awareness Campaign
 - 2012-present: Promotion and observance of International ME/CFS Awareness Day
 - 2012-present: SEC Calls
 - 2006-present: Webpage, patient/provider toolkits, Voice of the Patient

CDC's ME/CFS Activities – Implementation (Research to Refine Problem)

- 1995-1997 – Sero-epidemiology/immune function case vs. controls
- 2002-2003 – Wichita multidisciplinary study of case vs. controls
 - Sleep, cognition, neuroendocrine, ANS, cytokines, genomics
- 2004-2009 – Georgia multidisciplinary study of case vs. controls
 - Neuroimaging, neuroendocrinology, genomics
- 2012-2020 – MCAM sub-studies
 - CPET, cognition, NK cell function, biorepository
- 2015 – MCAM data used by IOM in developing clinical case definition
- 2018 – Participation in ME/CFS Common Data Element project
- 2021 – Implementation research on multi-disciplinary care in FQHC

CDC's ME/CFS Activities - Evaluation

- Communications with stakeholders
- Metrics on CMEs and webpage usage
- Longitudinal measures of KABs on surveys
- Program review with division leadership and outside peer review

Partnership examples

- ME/CFS Clinician Coalition
 - Website included as resource on CDC's ME/CFS pages and vice versa
- Department of Education and Center for Parent Information & Resources
 - Landing page on ME/CFS and Educational Support
- “Call-to-Action: Urge your State Health Department to Track ME!” from #MEAAction
 - Successful adoption of ME/CFS optional module in BRFSS
- University of Quinnipiac (Dr. Howard Selinger)
 - Medical student evaluation of standardized patient modules
- Solve ME/CFS Initiative
 - Shared image for International ME/CFS Day campaign

Multisite Clinical Assessment of ME/CFS (protocols closed 2020)

- Partnership with ME/CFS specialty clinics
- Data shared with IOM Committee on ME/CFS
- Biorepository – under construction, plan to partner with NIH
- Publications
 - Methods – main protocol, NK cell function, and medication information extraction
 - PROMIS Fatigue validation
- Manuscripts in preparation
 - Exercise challenge (under review)
 - Cognition (abstract at IACFSME meeting)
 - Orthostatic Intolerance (single site)
 - Heterogeneity not explained by site differences
 - NK cell function study



ME/CFS in the Time of COVID

- Essential to use PCC to shine light on ME/CFS, post-infectious illnesses and similar conditions
- Magnitude and “observability” of Post-COVID Conditions (PCC) is changing attitudes towards ME/CFS
 - ‘Post-exertional malaise is real’, statement on limits of current understanding
- CDC’s COVID Response includes Post-COVID Conditions
 - Epidemiology and Surveillance Task Force
 - CVDB ME/CFS personnel are deployed to PCC Team
 - Several PCC projects address PCC and include ME/CFS

Lessons on Partnerships from Other Programs

- **Wendy Ruben** – Making Friends: Collaborating and Cooperating
 - National Center for Birth Defects and Developmental Disabilities
- **Michele Walsh** – Partnering for Success: Lessons from the Division of Population Health
 - National Center for Chronic Disease Prevention and Health Promotion
- **Judith Griffith** – *CDC Let's Stop HIV Together*: Reducing Stigma through Promotion of HIV Resources, Division of HIV Prevention
 - National Center for HIV, VH, STD and TB Prevention

Thank you

For more information, contact CDC
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TTY: 1-888-232-6348 www.cdc.gov

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

