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”
Public Health Approach

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

Needs Assessment

Planning

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

Intervention

Research
- Refine understanding of problem
- Identify interventions

Effectiveness/Impact
- Are interventions working

Sustainability
- Resources sufficient to continue

Efficiency/Relevance

Partnerships
Essential for success and amplification

Evaluation

Turnock 1997
CDC’s ME/CFS Activities – Planning (Surveillance/Epidemiology)

- 2012 – 2020: Multisite Clinical Assessment of ME/CFS – ME/CFS expert clinics
- 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 #MEAction
  - 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