CDC Report for CFSAC
December 10, 2013

Ermias Belay, M.D.
Director (Acting) Division of High-Consequence Pathogens and Pathology
Activities to Improve Health Services for CFS

- Educational initiatives
- Validate CFS phenotypes and outcome measures
- Collaborations and outreach
Chronic Fatigue Syndrome

EDUCATIONAL INITIATIVES
New MedScape Roundtable CME/CE course

A Case-based Approach to CFS

- Targeting primary care physicians using MedScape subscribers
- Pre- and post-course questions gather data about knowledge and practices
- Required CME questions focus on key learning objectives
- Cases include pediatric CFS
- Link is available on CDC CFS webpage

Statistics as of October 30, 2013
- 10,675 learners
- 2,037 CME/CE issued

Moderator: Anthony Komaroff, MD
Panelists: Lisa W. Corbin, MD, Benjamin H. Natelson, MD and Peter C. Rowe, MD
Collaboration with CDC Academic Partnerships to Improve Health (APIH)

- APIH distributed links to CFS CMEs through Association of American Medical Colleges public health list-serve.
  - Diagnosis and Management of CFS
  - Sleep Problems in CFS
  - Medscape’s A Case-Based Approach to Chronic Fatigue Syndrome
Multi-site Clinical Assessment of Chronic Fatigue Syndrome

VALIDATE PHENOTYPES AND OUTCOME MEASURES
Study Objectives and Design

- Capitalize on clinical expertise of physicians experienced in care and treatment of CFS patients
- Collect standardized data on major illness domains of CFS from patients in these practices
  - Describe heterogeneity of CFS patients between practices
  - Evidence-based data to address case definition and CFS-subgroups
- Enrollment criteria: Any patient (18-70 years old) diagnosed with CFS in participating clinics
  - Exclusions: HIV +, age at diagnosis older than 62 years
Participating Clinics

- Beth Israel Medical Center, New York City NY
  - Benjamin Natelson, MD

- Institute for Neuro Immune Medicine, Miami FL
  - Nancy Klimas, MD

Open Medicine Institute Consortium

- Fatigue Consultation Clinic, Salt Lake City UT
  - Lucinda Bateman, MD

- Hunter-Hopkins Center, Charlotte NC
  - Charles Lapp, MD

- Open Medicine Clinic, Mountain View CA
  - Andreas Kogelnik, MD

- Richard Podell Medical, Summit NJ
  - Richard Podell, MD

- Sierra Internal Medicine, Incline Village NV
  - Daniel Peterson, MD
Protocol

- Developed by participating clinics and CDC
  - Fit into clinic routine as much as possible
  - Minimize burden to patients

- IRB approved

- Phase 1 – Cross-sectional data
  - Physical examination at time of clinic visit (or within one year)
  - Questionnaires for self-reported measures of illness
    - Patient completed
  - Data abstraction of medical records by clinic personnel
Status of Stage 1

- 471 CFS patients enrolled, exceeding target of 450
- Data cleaning and analysis is in progress
- Analyses will be shared with IOM committee
Stage 2 of Multi-site CFS Study

- Follow-up of CFS patients enrolled in Stage 1 (all clinics)
  - Saliva for morning cortisol profile
  - Blood for DNA and RNA

- Additional studies at some clinics
  - Enroll healthy controls and ill comparison group
  - Enroll pediatric/adolescent CFS patients and controls
  - Cognition and exercise testing

- IRB approval for follow-up protocol and collection of biologics received May 2013
  - Protocols for pediatric, cognition and exercise under IRB review
Stage 3 of Multi-site CFS Study

- Contractor meeting November 6-7, 2013 at CDC
- Plan to develop protocol to include:
  - Follow-up data on all those enrolled in stage 2 study
  - Serum sample for archiving
  - Centralized testing of NK cell numbers and function
  - Enrollment of patients within 1-2 years of illness onset
  - Enrollment severely ill/homebound patients
Advance recognition and treatment of CFS

COLLABORATIONS AND OUTREACH
Advocacy Group Collaborations

- CFS Patient Centered Outreach and Communication Activity (PCOCA Call)
  - One hour conference call format
    - 15 min. update from CFS program, 20 min. talk from invited expert,
    - 25 min. answers to questions from PCOCA mailbox
  - Third call September 10, 2013
    - Ian Lipkin, MD – Invited expert – “Infection and Immunity in CFS”
    - Increased call lines – 155 lines in use for call
    - Summary of call is in CDC clearance
    - Will be posted on CDC CFS web page