

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

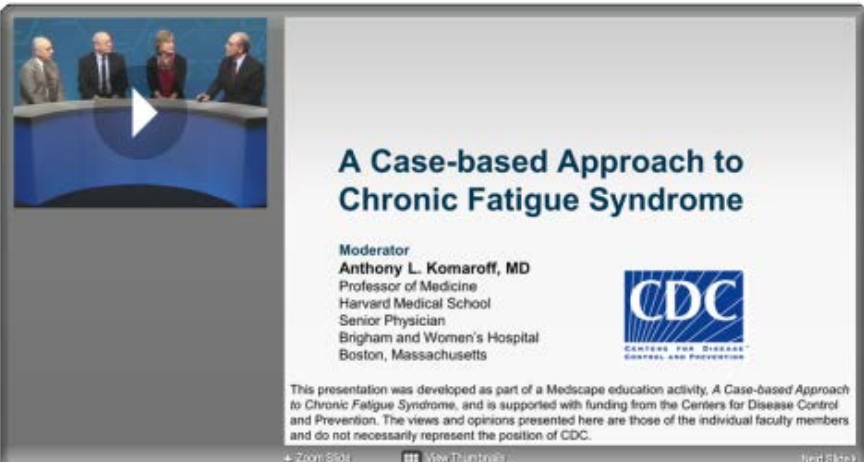
From Medscape Education Family Medicine

A Case-Based Approach to Chronic Fatigue Syndrome CME

Lisa W. Corbin, MD; Anthony L. Komaroff, MD; Benjamin H. Natelson, MD; Peter C. Rowe, MD Faculty and Disclosures
CME Released: 04/19/2013, Valid for credit through 04/19/2014

Supported by a contract from the Centers for Disease Control and Prevention

[Download Slides](#) [Transcript](#) [CME Information](#) [Earn CME Credit](#)



A Case-based Approach to Chronic Fatigue Syndrome

Moderator:
Anthony L. Komaroff, MD
Professor of Medicine
Harvard Medical School
Senior Physician
Brigham and Women's Hospital
Boston, Massachusetts

Panelists:
Lisa W. Corbin, MD
Benjamin H. Natelson, MD
Peter C. Rowe, MD

This presentation was developed as part of a Medscape education activity, A Case-based Approach to Chronic Fatigue Syndrome, and is supported with funding from the Centers for Disease Control and Prevention. The views and opinions presented here are those of the individual faculty members and do not necessarily represent the position of CDC.

[Zoom Slide](#) [View Transcript](#) [Next Slide](#)

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

Additional Educational Initiatives

- ❑ **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

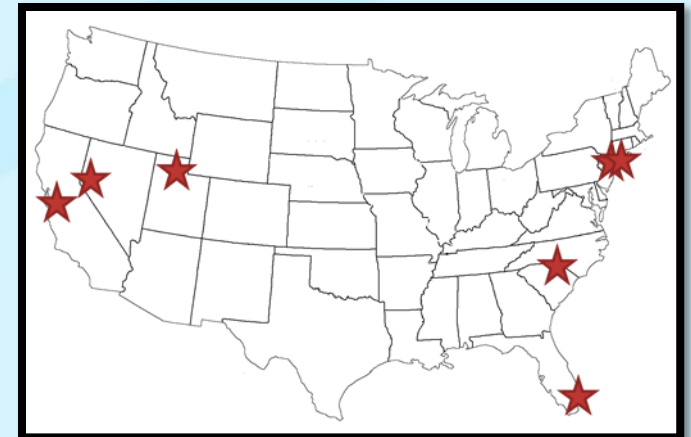
- ❑ **Capitalize on clinical expertise of physicians experienced in care and treatment of CFS patients**
- ❑ **Collect standardized data on major illness domains of CFS from patients in these practices**
 - Describe heterogeneity of CFS patients between practices
 - Evidence-based data to address case 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