

Agenda

Tuesday, December 9, 2014

- 8:30 a.m. **Opening Remarks**
James M. Anderson, M.D., Ph.D.
Director
Division of Program Coordination, Planning, and Strategic Initiatives
Office of the Director
National Institutes of Health
- 8:40 a.m. **Charge to the Panel**
David M. Murray, Ph.D.
Associate Director for Prevention
Director
Office of Disease Prevention
Division of Program Coordination, Planning, and Strategic Initiatives
Office of the Director
National Institutes of Health
- 8:50 a.m. **Workshop Overview and Panel Activities**
Carmen R. Green, M.D.
Associate Vice President and Associate Dean for Health Equity and Inclusion
Professor of Health Management and Policy, Anesthesiology, and Obstetrics
and Gynecology
Office for Health Equity and Inclusion
University of Michigan Health System
- 9:00 a.m. **Overview of Topic**
Susan E. Maier, Ph.D.
Deputy Director
Office of Research on Women's Health
Office of the Director
National Institutes of Health
- 9:20 a.m. **Patient Perspective**
Robert Miller
Patient and Advocate
- 9:40 a.m. **Case Definition Presentation**
Leonard A. Jason, Ph.D.
Professor of Psychology
Director
Center for Community Research
DePaul University
- 10:00 a.m. **Break**

Attendees will be responsible for meals and/or light refreshments on their own, at their own expense. The government and/or government contractors are not involved in facilitating the provision of food and/or light refreshments.

Tuesday, December 9, 2014 (continued)

Session 1: What is the incidence and prevalence of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and whom does it affect?

10:20 a.m. **Evidence-based Practice Center I: Overview of Systematic Review Methodology**

Heidi D. Nelson, M.D., M.P.H.

Medical Director of Cancer Prevention and Screening

Providence Cancer Center

Providence Health and Service

Vice-Chair and Research Professor

Departments of Medical Informatics and Clinical Epidemiology

Pacific Northwest Evidence-based Practice Center

Oregon Health & Science University

10:40 a.m. **Quantifying ME/CFS in the Population: Consideration of Case Definition and Insights From Gulf War Illness and Other Symptom-Defined Conditions**

Lea Steele, Ph.D.

Director

Veterans Health Research Program

Institute of Biomedical Studies

Baylor University

11:00 a.m. **Social Determinants of Health**

Abigail A. Brown, M.A.

Doctoral Candidate

Clinical-Community Psychology

DePaul University

11:20 a.m. **Epidemiology of ME/CFS: Making Sense of What We Know**

Luis Nacul, M.D., Ph.D., M.F.P.H.

Chief Investigator

CURE-ME

London School of Hygiene & Tropical Medicine

11:40 a.m. **Discussion**

12:20 p.m. **Lunch (at the expense of the attendee)**

Session 2: Given the unique challenges to ME/CFS, how can we foster innovative research to enhance the development of treatments for patients?

1:20 p.m. **Incorporating Multiple Study Designs Into ME/CFS Research**

Dedra Buchwald, M.D.

Professor of Epidemiology and General Internal Medicine

Center for Clinical and Epidemiological Research

University of Washington School of Public Health

Tuesday, December 9, 2014 (continued)

1:40 p.m. **Maximizing Approaches and Results From the Study of Other Illnesses and Complex Chronic Conditions**

Daniel J. Clauw, M.D.

Professor of Anesthesiology, Medicine, and Psychiatry

University of Michigan Medical School

Director

Chronic Pain and Fatigue Research Center

University of Michigan Medical Center

2:00 p.m. **Using Research on Co-Morbidities To Understand ME/CFS**

Niloofer Afari, Ph.D.

Associate Professor

University of California, San Diego Healthcare System

Director of Clinical Research

Veterans Affairs (VA) Center of Excellence for Stress and Mental Health

Division Co-Director

Mental Health Integrative and Consultative Services

VA San Diego Healthcare System

2:20 p.m. **Discussion**

3:00 p.m. **Break**

Session 3: What does research on ME/CFS tell us about the presentation and diagnosis of ME/CFS in the clinic?

3:20 p.m. **Evidence-based Practice Center II: Studies of Diagnostic Methods**

M.E. Beth Smith, D.O.

Associate Professor

Department of Medical Informatics and Clinical Epidemiology

Pacific Northwest Evidence-based Practice Center

Oregon Health & Science University

3:40 p.m. **Leading Questions Always Collect Inaccurate Information: Lessons From Current Treatments and Clinical Trials**

Christopher R. Snell, Ph.D.

Scientific Advisory Committee Chair

The Workwell Foundation

4:00 p.m. **Comparative Effectiveness Research**

Andreas M. Kogelnik, M.D., Ph.D.

Founder and Director

Open Medicine Institute

4:20 p.m. **The Future of Self-Management in ME/CFS**

Fred Friedberg, Ph.D.

Research Associate Professor of Psychiatry and Behavioral Science

Stony Brook University

4:40 p.m. **Discussion**

5:15 p.m. **Adjourn**

Wednesday, December 10, 2014

Session 4: What tools, measures, and approaches help define individuals with ME/CFS?

- 8:30 a.m. **Evidence-based Practice Center III: Treatment: Medications and Complementary and Alternative Medicine**
Heidi D. Nelson, M.D., M.P.H.
Medical Director of Cancer Prevention and Screening
Providence Cancer Center
Providence Health and Service
Vice-Chair and Research Professor
Departments of Medical Informatics and Clinical Epidemiology
Pacific Northwest Evidence-based Practice Center
Oregon Health & Science University
- 8:50 a.m. **Evidence-based Practice Center IV: Treatment: Counseling Therapies and Exercise**
M.E. Beth Smith, D.O.
Associate Professor
Department of Medical Informatics and Clinical Epidemiology
Pacific Northwest Evidence-based Practice Center
Oregon Health & Science University
- 9:10 a.m. **Overview of Existing Tools and Measures**
Benjamin H. Natelson, M.D.
Director
Pain and Fatigue Study Center
Mount Sinai Beth Israel
Professor of Neurology
Icahn School of Medicine at Mount Sinai
- 9:30 a.m. **Measures: Patient-Reported and Physiologic**
Elizabeth R. Unger, Ph.D., M.D.
Chief
Chronic Viral Diseases Branch
Division of High-Consequence Pathogens and Pathology
National Center for Emerging and Zoonotic Infectious Diseases
Centers for Disease Control and Prevention
- 9:50 a.m. **Innovative Approaches in Fatigue Research: Phenotyping, Biomarker Discovery, and Statistics**
Leorey N. Saligan, Ph.D., R.N., CRNP, FAAN
Investigator
Symptom Management Branch
National Institute of Nursing Research
National Institutes of Health
- 10:10 a.m. **The Role of the Immune System in ME/CFS**
Mady Hornig, M.D., M.A.
Director of Translational Research
Center for Infection and Immunity
Associate Professor of Epidemiology
Columbia University Mailman School of Public Health

Wednesday, December 10, 2014 (continued)

Session 5: How are tools and measures used to distinguish subsets of patients with ME/CFS?

- 10:30 a.m. **Discussion**
- 11:30 a.m. **Break**
- 11:50 a.m. **Identification of Subsets of Individuals**
Nancy G. Klimas, M.D.
Director
Miami Veterans Affairs Gulf War Illness and ME/CFS Research Program
Professor and Chairperson
Department of Clinical Immunology
Scientific Director
Institute for Neuro-Immune Medicine
Nova Southeastern University
- 12:10 p.m. **Subtypes of CFS/ME: New Discoveries and Unanswered Questions**
Renée R. Taylor, Ph.D.
Vice Provost for Faculty Affairs
Licensed Clinical Psychologist
Professor
Department of Occupational Therapy
University of Illinois at Chicago College of Allied Health Sciences
- 12:30 p.m. **What Outcomes Represent Improvement, Recovery, Prevention, Benefits, or Harms?**
Suzanne D. Vernon, Ph.D.
Scientific Director
Solve ME/CFS Initiative
- 12:50 p.m. **Discussion**
- 1:20 p.m. **Workshop Wrap-Up/Next Steps**
- 1:30 p.m. **Adjourn**