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.
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.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
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

Using Research on Co-Morbidities To Understand ME/CFS
Niloofar 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

Discussion

Break

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

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

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

Comparative Effectiveness Research
Andreas M. Kogelnik, M.D., Ph.D.
Founder and Director
Open Medicine Institute

The Future of Self-Management in ME/CFS
Fred Friedberg, Ph.D.
Research Associate Professor of Psychiatry and Behavioral Science
Stony Brook University

Discussion

Adjourn
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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
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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