



## AGENDA : 3 APRIL 2024

**08:00** Registration

**09:00** Welcome and Opening Remarks

### PART 1

#### SESSION 1

**09:30**

#### **Susan Levine**

MD Center for Solutions at Columbia Mailman School of Public Health; Research Fellow Center for Ener-  
vating Disorders at Cornell University; private practice in ME/CFS and related disorders

**Brief History of 'Pandemics' Related to ME/CFS Punta Gorda Florida and Royal Free  
Hospital in London. Origin of Current Case Definition**

#### SESSION 2

**10:00**

#### **David Systrom**

MD PhD Director, Dyspnea Center & Advanced Cardiopulmonary Exercise Testing Program, BWH; Co-Di-  
rector, Ronald Tompkins Harvard ME/CFS Collaborative Research Center; Assistant Professor of Medicine,  
Harvard Medical School

**The Nexus Between ME/CFS and Long Covid: Insights from the NIH RECOVER Initiative  
and the NIH ME/CFS and Long COVID Commonalities Task Force**

#### SESSION 3

**10:30**

#### **Elizabeth Unger**

MD, PhD, Chief Chronic Viral Diseases Branch Division of High Consequence Pathogen and Pathology, Na-  
tional Center for Emerging and Zoonotic Infectious Diseases. US Centers for Disease Control and Prevention

**Public Health Approach to ME/CFS and Post-Acute Infection Syndromes: Experience of  
the US Centers for Disease Control and Prevention**

**11:00** Coffee break

**PART 2:** Will cover : ME/CFS, Long Covid and co-occurring conditions, diagnosis, treatment approaches (small fiber neuropathy, mast cell activation syndrome/MCAS, hypermobile EDS, postural orthostatic tachycardia syndrome/POTS, Fibromyalgia, others). Chairs: Antonio Vaz Carneiro and Mario Santos Cardiologist - Hospital Lusíadas Porto.

SESSION 4



**Lucinda Bateman**

MS MD, Medical Director, Bateman Horne Center, Salt Lake City, Utah, USA

**Covid Long haulers, Presentation of Long COVID and Post-Viral Syndromes, Common Comorbidities of Long COVID and the Design of Simple Treatment Plans**

SESSION 5



**Luis Nacul**

MD PhD University of British Columbia; London School of Hygiene and Tropical Medicine; BC Women's Hospital

**Treatment of ME/CFS: Beyond the NICE Guidelines on Diagnosis, and Recommendations from Europe and North America** (in Portuguese with English power point slides)

SESSION 6



**Eliana Lacerda**

MD, PhD London School of Hygiene and Tropical Medicine; CureME research group

**A Prospective Cohort from the UK ME/CFS Biobank (UKMEB): Participants with Mild/Moderate or Severe ME/CFS** (in Portuguese with English Power point slides)

**13:00**

**Lunch**

SESSION 7



**Susan Levine**

MD Center for Solutions at Columbia Mailman School of Public Health; Research Fellow Center for Enervating Disorders at Cornell University; private practice in ME/CFS and related disorders

**António Vaz Carneiro**

MD PhD President of the Institute for Evidence-Based Health at the University of Lisbon Medical School; Director of Cochrane Portugal

**Joan Serra Hoffman**

PhD, Conference Executive Committee; Millions Missing Aliança

**Conversation: The Role of Physician as Advocate, Lessons Learned from 30 Years of Clinical Practice**

SESSION 8



**Ed Yong**

Pulitzer-winning science writer

**3 Years of Covering COVID, Long COVID and ME/CFS: What You Need to Know. Lessons learned by Pulitzer Prize winner in Explanatory Journalism**

## SESSION 9

**Moderator: Joan Serra Hoffman**

PhD, Conference Executive Committee; Millions Missing Aliança

**Sonya Chowdhury**

Chief Executive Officer at Action for M.E.; Non-Executive Director, Curo; Chair: World ME Alliance; DecodeME Study

**15:30****Sian Leary**

Head of Advocacy and Communications, World ME Alliance

**Muna Sidarus**

MS, Medical Student at the University of Algarve; Myos managing board member

**Monica Andersen Morais**

MBA, Volunteer organizer, Millions Missing Aliança

**Patient advocate panel****16:00****Coffee break**

## SESSION 10

**Moderator: João Carlos Winck**

MD PhD Professor of Respiratory Medicine at the Faculty of Medicine, University of Porto; Coordinator of the Respiratory Medicine Unit of Instituto CUF Porto

**16:30****Johanna Squires**

MSc Senior research coordinator for Dr. David Systrom at Brigham and Women's Hospital in Boston, Massachusetts

**Sarra Maan Al-Zyed**

BS from Cornell University; Research Assistant at Dr. David Systrom's lab at the Brigham and Women's Hospital in Boston

**João Malato**

PhD student in Computational Biology, Centre of Statistics and its Applications at the University of Lisbon

**Young Investigator Panel: Insights on Getting Involved in ME/CFS and Long Covid Research and Initiating and Running Clinical Trials****17:00****Spillover / Discussion**

## SESSION 11

**Jaime Branco**

MD PhD Professor NOVA Medical School (NMS) at NOVA University of Lisbon

**17:30****Nuno Sepúlveda**

PhD Warsaw University of Technology; Centre of Statistics and its Applications at the University of Lisbon

**Reflections and Implications for Clinical Practice and Policies in Portugal****18:00****Closing**



## AGENDA : 4 APRIL 2024

**08:00** Registration

**08:45** Welcome and Opening Remarks

### PART 3

#### SESSION 12

**09:00**

**Linda Tannenbaum**

MS Founder and CEO, Open Medicine Foundation

**Complex Diseases Require Open and International Collaboration**

#### SESSION 13

**09:30**

**David Systrom**

MD, PhD Director, Dyspnea Center & Advanced Cardiopulmonary Exercise Testing Program, BWH; Co-Director, Ronald Tompkins Harvard ME/CFS Collaborative Research Center; Assistant Professor of Medicine, Harvard Medical School

**Dyspnea in ME/CFS and Long COVID**

#### SESSION 14

**10:00**

**Phillip Joseph**

MD, Associate Director, Yale University Pulmonary Vascular Program Pulmonary, Critical Care, and Sleep Medicine

**Neurovascular Dysregulation in ME/CFS**

#### SESSION 15

**10:30**

**Inderjit Singh**

MD FRCP FCCP, Assistant Professor of Medicine Yale School of Medicine, Division of Pulmonary Critical Care and Sleep Medicine; Director Pulmonary Vascular Program, Yale New Haven health system

**Pathogenesis of Exercise Intolerance in Long COVID**

**11:00** Coffee break

## PART 4

## SESSION 16

11:30

**Rudolf Oliveira**

MD PhD. Associate Professor; Head, Pulmonary Hemodynamic Assessment Program, Pulmonary Vascular Disease Service & Pulmonary Function and Exercise Physiology Unit, Division of Respiratory Diseases, Federal University of Sao Paulo (Unifesp), Brazil

**Diagnostic Workup in ME/CFS and Long COVID** (in Portuguese with English power point slides)

## SESSION 17

12:00

**Mario Santos**

MD, PhD, Centro Hospitalar Universitário do Porto, School of Medicine; Biomedical Sciences of University of Porto, ICBAS-UP

**Diagnosis and Treatment of ME/CFS and Long COVID: A Cardiology Perspective** (in Portuguese with English power point slides)

## SESSION 18

12:30

**Jonas Bergquist**

MD PhD Biomedical Centre, Uppsala University; Chief Medical Officer & Director – The ME/CFS Collaboration at Uppsala University, Open Medicine Foundation

**Metabolic Profiling of ME Patients under Mild Exertion during Home-visits**

13:00

Lunch

## SESSION 19

14:30

**Nuno Sepúlveda**

PhD Warsaw University of Technology; Centre of Statistics and its Applications at the University of Lisbon

**Research Challenges in ME/CFS and Long COVID in the Era of Machine Learning and Artificial Intelligence** (in Portuguese with English power point slides)

## SESSION 20

15:00

**Maureen Hanson**

PhD Department of Molecular Biology and Genetics; Director of Center for Energizing NeuroImmune Disease at Cornell University; Open Medicine Foundation Scientific Advisory Board member

**Circulating Signals of ME/CFS in Response to Exercise**

## SESSION 21

15:30

**Carmen Scheibenbogen**

MD Internal Medicine physician; ME/CFS doctor and Deputy Chair, Institute of Medical Immunology at the University Hospital Charité in Berlin, Germany

**Autoimmunity in ME/CFS and Post COVID Syndrome and Treatment Trials**

**16:00** Coffee break

SESSION 22



**Wenzhong Xiao**

PhD. Computational Research Center for Complex Chronic Diseases, Massachusetts General Hospital;  
Co-Director, Ronald Tompkins Harvard ME/CFS Collaborative Research Center

**Severely Ill Patient Big Data Study and Comparing ME / CFS with other diseases**

**17:00** Spillover / Discussion

SESSION 23



**Nuno Sepúlveda**

PhD Warsaw University of Technology; Centre of Statistics and its Applications at the University of Lisbon

**António Vaz Carneiro**

MD PhD President of the Institute for Evidence-Based Health at the University of Lisbon Medical School;  
Director of Cochrane Portugal

**Reflections and Implications for Research and Scientific Collaborations in Portugal**

**18:00** Closing