AGENDA: 3 APRIL 2024

08:00 Registration

**09:00** Welcome and Opening Remarks

PART 1

SESSION 1



### 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

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

SESSION 2



### **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

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



### Elizabeth Unger

MD, PhD, Chief Chronic Viral Diseases Branch Division of High Consequence Pathogen and Pathology, National 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

10:30 Panel Discussion: Susan Levine, David Systrom, Elizabeth Unger

11:00 Coffee break

PART 2



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)

# 12:40 Panel Discussion: Luis Nacul and Eliana Lacerda

### 13:10 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

# 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



# 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





#### Jaime Branco

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

# 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

### Linda Tannenbaum

MS Founder and CEO, Open Medicine Foundation

Complex Diseases Require Open and International Collaboration

SESSION 13



# **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

# Phillip Joseph

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

Neurovascular Dysregulation in ME/CFS



SESSION 15

# 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

10:30 Panel Discussion: David Systrom, Phillip Joseph, Inderjit Singh

11:00 Coffee break

PART 4

SESSION 16



### 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



#### 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)

12:10

#### SESSION 18

# 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

12:30 Panel Discussion: Rudolf Oliveira, Mario Santos, Jonas Bergquist

13:00 Lunch



SESSION 19 \*

# 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)

15:00

SESSION 20 \*

# Maureen Hanson

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

Circulating Signals of ME/CFS in Response to Exercise

\* Speakers will have 20min for presentation and 10min for Q/A (or 25/5 if that is more appropriate)



SESSION 21 \*

# 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

\* Speakers will have 20min for presentation and 10min for Q/A (or 25/5 if that is more appropriate)