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**ME FORENINGEN**

Rådhusstrøget 1,1

3520 Farum

+45 4495 9700

mail@me-foreningen.dk

www.me-foreningen.dk

### **Open Letter to Danish Health Politicians**

On March 14th 2019, a unified Danish Parliament voted to acknowledge WHO's diagnostic classification of Myalgic Encephalomyelitis (ME - G93.3) as a biological illness and to separate ME from Functional Disorders.

The proposal passed is aligned with the current international scientific knowledge about ME.

Based on analysis of more than 9.000 peer-reviewed studies, the Institute of Medicine<sup>1</sup>, Centers for Disease Control (CDC), National Institutes of Health (NIH), as well as the advisory report from the Dutch Health Council<sup>2</sup>, conclude that ME is a serious chronic multisystem, biological disease that substantially limits the activities and quality of life of patients.

ME is a complex and physical disease for which there is currently no cure. It is not a psychological or psychosomatic disease. There is strong scientific evidence of neurological/autonomic dysfunction, immunologic and inflammatory pathologies, microbiome perturbation, metabolic/mitochondrial as well as cardiac abnormalities (and more) in patients.

Based on this scientific evidence, there is an imminent need to change the narrative of ME to avoid that patients are misdiagnosed or further stigmatized by falsely equating the disease with (chronic or unexplained) fatigue, deconditioning or psychosomatic classifications, like functional disorders, medically unexplained symptoms, somatoform disorders, somatic symptom disorder, functional somatic syndrome, neurasthenia, or bodily distress disorder/syndrome.

Patients have for decades been prescribed treatments like Cognitive Behavioral Therapy (CBT) and Graded Exercise Therapy (GET), based on the idea that they suffer from "false illness beliefs", fear of exercise or that they are deconditioned. This 'deconditioning hypothesis' as well as the 'psychosomatic hypothesis' of ME is not supported by biomedical research. The treatments based on these hypotheses (CBT/GET) have produced no robust evidence in the past two decades, as the US Agency for Healthcare Research and Quality systematic literature review, and reanalysis of the largest ever study on CBT/GET (PACE trial)<sup>3</sup> have shown.

The CDC has recently removed its recommendations for CBT and GET from its website.

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<sup>1</sup> IOM 2015 report

<sup>2</sup> <https://www.gezondheidsraad.nl/en/task-and-procedure/areas-of-activity/optimale-gezondheidszorg/mecfs>

<sup>3</sup> <https://bmcpyschology.biomedcentral.com/articles/10.1186/s40359-018-0218-3>

Furthermore, and of dire importance, patients internationally for more than 20 years have continually reported deterioration from following the advice of their doctors to gradually increase their exertion levels based on a GET protocol.

Post-exertional malaise (PEM), a worsening of symptoms after minimal physical or mental exertion, is the hallmark characteristic of the disease. GET worsens PEM and has the potential to cause lasting harm for patients with ME.

There is international consensus that funding biomedical ME research is the only way to create better insights into the physiological mechanisms of this debilitating disease, so we can provide better and more efficient care, based on the needs of patients and the biomedical nature of the disease, as well as effective treatments and potentially a cure. Biomarkers are also needed for accurate diagnosis.

More funding for biomedical research into ME is therefore urgently needed.

We ask that the Danish Government will strongly consider a long-term investment in biomedical ME research. It is an absolute priority and the only way to make the necessary progress to help stop what the CDC calls a “hidden health crisis”.

We would be happy to provide you with further insights based on our expertise, if needed.

This letter has also been sent to the Minister of Higher Education and Science, as well as the Danish Health Authority.

Sincerely

## **DENMARK**

### **Kim Varming**

Ledende overlæge  
Klinisk Immunologisk Afdeling  
Aalborg Universitetshospital

### **Rikke Katrine Jentoft Olsen, MSc, PhD**

Associated Professor  
Research Unit for Molecular Medicine  
Department for Clinical Medicine  
Aarhus University

### **Henrik Nielsen, MD, DMSC**

Specialist i intern medicin og reumatologi  
Medlem af Radikale Venstres bestyrelse i Gentofte og Region Hovedstaden  
MC Members of CA15111 - Member of European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (EUROMENE)

### **Jesper Mehlsen**

Speciallæge  
Klinik Mehlsen,  
Peter Bangs Vej 7A, 2000 Frederikesberg  
Seniorforsker  
Enhed for Kirurgisk Patofysiologi  
Juliane Marie Center

Rigshospitalet

**Ana C. Gonzalez Ebsen** <sup>[L]</sup><sub>[SEP]</sub> **PhD Student**  
Molekylær Medicinsk Forskningsenhed (MMF)  
Aarhus University, Denmark

**Ole Næsh Hendriksen**  
Speciallæge, dr.med.  
Klinik Mehlsen  
Peter Bangs Vej 7A  
2000 Frederiksberg

**Paula Fernandez Guerra, PhD, MSc**  
Biomedical researcher  
Research Unit for Molecular Medicine  
Aarhus University Hospital  
Denmark

## **SWEDEN**

**Jonas Bergquist**  
Professor Uppsala University  
MC Members of CA15111 - European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome  
(EUROMENE)  
Sverige

**Sture Eriksson**  
Associated Professor  
Vice chairmen  
Swedish RME Association

**Bo C. Bertilson** <sup>[L]</sup><sub>[SEP]</sub> **MD, PhD**  
Research leader Bragee clinics and Musculoskeletal functions and pain <sup>[L]</sup><sub>[SEP]</sub>  
Div. Family Medicine and Primary Care, NVS <sup>[L]</sup><sub>[SEP]</sub> Karolinska Institutet  
Academic Primary Health care Center

**Anders Rehnström**  
Specialistläkare  
ME-Mottagningen  
Stora Sköndal  
Stockholm

**Åsa Andersson**  
VD / Direktör  
Stora Sköndal, Sverige

**Sven Britton**  
Tidl. professor i infektionssjukdomar  
Karolinska Institutet  
Sverige

**Dr Per Julin, MD, PhD**

Institution for Neurobiology, Care Sciences and Society (NVS)  
Karolinska Institutet

<https://medarbetare.ki.se/people/perjul>

Senior Consultant

ME/CFS-poliklinik, Neurological Rehabilitation Clinic

Stora Sköndal

[https://www.storaskondal.se/vara-verksamheter/neurologisk\\_rehabilitering/mecfs-mottagning/](https://www.storaskondal.se/vara-verksamheter/neurologisk_rehabilitering/mecfs-mottagning/)

Expert in SBU (Swedish Agency for Health Technology Assessment and Assessment of Social Services)  
review of ME/CFS:

<https://www.sbu.se/en/publications/sbu-bereder/myalgic-encephalomyelitis-and-chronic-fatigue-syndrome-mecfs/>

**Muhammad Rizwan**

MS Infection Biology

Associate Researcher

Clinical Microbiology Uppsala University Hospital, Sweden

**Petter Brodin**

Senior Researcher & physician

Department of pediatrics

Karolinska University Hospital

**Eirini Apostolou, Ph.D**

Dept. of Clin. & Exp. Med.

Division of Cell Biology

Linköping University

58185 Linköping

Sweden

**Kumari Ubhayasekera (PhD)**

Department of Chemistry-BMC

Uppsala University

Uppsala, Sweden

**Carl-Gerhard Gottfries**

Professor Emeritus of Psychiatry

Gottfries Clinic Krokslätts Torg 5,

43137 Mölndal

**Wimal Ubhayasekera**

Uppsala University

Uppsala, Sweden

**Björn Bragée, MD**

Specialist in Pain Medicine,

Founder of ME-Center, Stockholm

## NORWAY

### **Olav Mella** Department director, professor

Department of Oncology and Medical Physics <sup>[1]</sup><sub>[SEP]</sub>  
Haukeland University Hospital, Bergen, Norway  
[www.helse-bergen.no](http://www.helse-bergen.no)

### **Per Ole Iversen**, Professor

Department of Nutrition  
University of Oslo,  
P.O. Box 1046 Blindern, 0317 Oslo

### **Ola Saugstad**

Professor emeritus MD, PhD, FRCPE  
Professor of Pediatrics at the University of Oslo.  
Director of Department of Pediatric Research  
Consultant in Neonatology  
Rikshospitalet, University of Oslo,  
Norway

### **Kristian Sommerfelt**

Pediatrician  
MD, PhD. Professor  
Haukeland University Hospital  
University of Bergen  
Bergen, Norway.

### **Tor Lea**

Professor emeritus, PhD  
Dept. of Chemistry, Biotechnology and Food Science  
Norwegian University of Life Sciences  
Ås, Norway

## FINLAND

### **Olli Polo**, MD, PhD

Specialist in Pulmonary Medicine  
Expert in Sleep Medicine  
Tampere University Hospital, Tampere, Finland

### **Markku Partinen**, MD, PhD, FAAN

Professor, Specialist in Neurology, Research Director  
Somnologist, ESRS, Expert in Sleep Medicine  
Helsinki Sleep Clinic, Vitalmed Research Centre  
Helsinki, Finland

## POLAND

### **Dr Pawel Zalewski**

Nicolaus Copernicus University in Torun Collegium Medicum in Bydgoszcz  
M. Skłodowskiej-Curie 9, Poland, Bydgoszcz  
EUROMENE MC Member

## **GERMANY**

### **Carmen Scheibenborgen**

Professor Dr. Med, Leiterin Immundefekt-Ambulanz  
FÄ für Hämatologie, Onkologie und Fachimmunologin. Charite,  
Berlin

### **Uta Behrends Prof. Dr. med.**

Pediatric haematooncologist  
CFS polyclinic  
Children's Hospital  
Technische Universität München  
Munich

## **BELGIUM**

### **Dr AM Uyttersprot**

Neurologist CFS  
Maria Theresialaan 33/6  
1800 Vilvoorde, Belgium

## **NETHERLANDS**

### **Prof Dr Frans C Visser, cardiologist**

ME/CFS specialist  
Stichting CardioZorg  
Planetenweg 5, 2132HN Hoofddorp, Holland

### **Dr C (Linda) MC van Campen, cardiologist**

ME/CFS specialist  
Stichting CardioZorg  
Planetenweg 5  
2132HN Hoofddorp, Holland

## **UNITED KINGDOM**

### **Dr Luis Nacul**

Clinical Associate Professor,  
London School of Hygiene and Tropical Medicine,  
London UK

### **Dr Charles Shepherd MB BS**

Hon Medical Adviser  
ME Association  
7 Apollo Office Court  
Radcliffe Road, Buckingham

### **Dr Nigel Speight**

Paediatrician  
Durham, UK

### **Derek Pheby**

Visiting Professor of Epidemiology,  
Buckinghamshire New University,

High Wycombe, England,  
MC Member of CA15111 - European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome  
(EUROMENE).

**Dr. K.N. Hng**

MBChB, MRCP, PG Cert in WBME, FHEA  
Author of "M.E. and Me: A Doctor's Struggle with Chronic Fatigue Syndrome"

**Professor Chris P Ponting**

University of Edinburgh  
MRC Human Genetics Unit

**Dr Sarah Myhill,**

Upper Weston,  
Llangunllo, Knighton,  
Powys LD7 1SL  
Author of the book "Diagnosis and Treatment of Chronic Fatigue Syndrome and Myalgic Encephalitis"

**Prof Simon Carding**

Head, Gut Microbes and Health Research Programme  
Quadram Institute Bioscience,  
Norwich Research Park, NR4 7UA

**Nina Muirhead BA(oxon) BMBCh(oxon)**

MRCS DOHNS MED PGDipDerm  
Specialty Doctor in Dermatologic Surgery  
Chair of CFS/ME Research Collaborative (CMRC) Education Working Group  
Buckinghamshire

**William Weir**

Consultant Physician  
London

**Tom Wileman**

Professor Molecular Virology  
Quadram Institute Bioscience  
University of East Anglia  
Norwich Research Park  
Norwich, NR4 7UQ

**Dr Cara Tomas**

Research associate,  
Newcastle University,  
Newcastle upon-Tyne, UK

**Dr Penny Powell**

Senior Lecturer in Cell and Molecular Virology  
Norwich Medical School, University of East Anglia  
Norwich Research Park  
Norwich NR4 7TJ, UK

**Dr Amolak S Bansal**

Consultant in Clinical Immunology, allergy and CFS/ME  
St Anthony's Hospital  
Cheap, SM3 9DW,  
England

**Dr Ben Marsh**

Consultant Neurodisability Paediatrician  
Clinical Director Community Paediatrics  
University Hospitals Plymouth NHS Trust  
England

**AUSTRIA****Francisco Westermeier**

Institute of Biomedical Science  
University of Applied Sciences, FH JOANNEUM  
Graz, Austria  
(CA15111) European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (EUROMENE)  
Management Committee: Austria

**ITALY****Professor Umberto Tirelli**

Senior visiting scientist National Cancer Institute  
Aviano Italy

**Dr. Paolo Cornelio Brambilla**

General Practitioner, Psychotherapist.  
Italian delegate at European M.E. Alliance  
Member of the Scientific Committee of CFS-ME ODV, Italy.

**SPAIN****Dr Jose Alegre, MD; PhD**

Vall d'Hebron University Hospital  
ME/CFS Clinical Unit  
Barcelona, Spain  
Email: [jalegre@vhebron.net](mailto:jalegre@vhebron.net)



**Dr Jesús Castro, PhD**

Vall d'Hebron University Hospital  
Mediterranea Research Bldg (VHIR)  
ME/CFS Research Unit  
Barcelona, Spain  
E-mail: [jesus.castro@vhir.org](mailto:jesus.castro@vhir.org)  
ORCID: <http://orcid.org/0000-0002-2481-3052>

**LATVIA**

**Uldis Berkis**, asoc. prof.  
Riga Stradins University  
Letland

**Modra Murovska**, MD, PhD;  
Riga Stradiņš University,  
Riga, Latvia;  
CA15111 Action Chair European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome  
(EUROMENE)  
Letland

**Zaiga Nora-Krukle, Ph.D**

Senior researcher at Institute of Virology and microbiology,  
Riga Stradins University  
COST action CA15111, MC substitute  
EATRIS coordinator of Latvia node

**BULGARIEN**

**Assoc.Prof. Evelina Shikova**  
Head NRL "Herpes and Oncogenic Viruses"  
National Center of Infectious and Parasitic Diseases  
Sofia,  
Bulgaria

**ROMANIA**

**Carmen-Adella Sirbu**  
Associate Professor of Neurology,  
Titu Maiorescu University  
Central Military Emergency University Hospital, Bucharest, Romania.  
MC Members of CA15111 - European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome  
(EUROMENE).

**SERBIA**

**Sekulic Slobodan**  
Full research professor  
MC member of CA15111  
Medical Faculty Novi Sad, Serbia

## USA

**Ronald G. Tompkins, M.D., Sc.D.**  
Sumner M Redstone Professor of Surgery  
Harvard Medical School  
Massachusetts General Hospital  
USA

**Linda Tannenbaum**  
Founder and CEO  
Open Medicine Foundation  
USA

**Robert D Phair PhD**  
Chief Science Officer  
Integrative Bioinformatics Inc  
Mountain View, CA  
USA

**Ronald W. Davis, PhD**  
Stanford University  
Director, Stanford Genome Technology Center  
Director, ME/CFS Collaborative Research Center at Stanford  
Director, Open Medicine Foundation Scientific Advisory Board  
USA

**Wenzhong Xiao**  
Assistant professor of Bioinformatics  
Director of the Inflammation & Metabolism Computational Center  
Harvard Medical School & Massachusetts General Hospital  
USA

**Mady Hornig, MA, MD<sup>4</sup>**  
Associate Professor of Epidemiology  
Columbia University Mailman School of Public Health  
USA

**Leonard A. Jason, Ph.D.** <sup>[SEP]</sup>  
Professor of Psychology | DePaul University  
Director, Center for Community Research  
990 W. Fullerton Ave., Suite 3119  
Chicago, IL 60614  
Telephone: 773-325-2018  
Website: <http://leonardjason.com/>  
USA

**Michael VanElzakker, PhD**  
Research Fellow, Neuroscience & Neurotherapeutics  
Harvard Medical School & Massachusetts General Hospital  
Instructor, Tufts University  
USA

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<sup>4</sup> Indeed, there is evidence that such approaches (CBT/GET) may not only be ineffective, but may actually be harmful to patients. (Davenport TE et al. **Checking our blind spots: current status of research evidence summaries in ME/CFS.** *Br J Sports Med* 2019;53:1198. doi: 10.1136/bjsports-2018-099553)

**Betsy Keller, PhD**

Professor, Exercise Science  
Ithaca College, Ithaca, NY  
Co-Coordinator, Clinical Core  
NIH-funded Collaborative Research Center for the Study of ME/CFS  
Cornell University, Ithaca, NY,  
USA

**H. Craig Heller, Professor**

Biology Department  
Stanford University  
Stanford, CA 94305-5020  
USA

**Jennifer Frankovich, MD MS**

Clinical Associate Professor  
Pediatric Rheumatology  
Stanford University  
Co-Director, Stanford PANS Clinic  
Director, Stanford PANS research program  
USA

**Mario R. Capecchi**

Distinguished Professor  
University of Utah School of Medicine  
USA

**Todd E. Davenport, PT, DPT, MPH, OCS**

Professor & Program Director  
University of the Pacific  
Thomas J. Long School of Pharmacy & Health Sciences  
Department of Physical Therapy  
USA

**Robert K. Naviaux, MD, PhD**

Professor of Genetics  
Biochemical Genetics and Metabolism  
Departments of Medicine, Pediatrics, and Pathology  
Co-director, The Mitochondrial and Metabolic Disease Center (MMDC)  
UCSD School of Medicine  
214 Dickinson St., Room C-107  
San Diego, CA 92103-8467  
USA

**Amel Karaa, MD**

Assistant Professor,  
Harvard Medical School  
Director, Mitochondrial Disease Program,  
Massachusetts General Hospital

**Lars Steinmetz, Ph.D.**

Professor of Genetics, Stanford University<sup>[[SEP]]</sup>  
Co-Director, Stanford Genome Technology Center<sup>[[SEP]]</sup>  
Principal Investigator & Senior Scientist, Genome Biology Unit, EMBL  
USA

**J. Mark VanNess, Ph.D.**

Professor - Health and Exercise Science  
University of the Pacific  
Stockton, CA 95211  
Scientific Advisor - WorkWell Foundation, Ripon, CA  
USA

**Derya Unutmaz, M.D.**  
Professor, Jackson Laboratory for Genomic Medicine  
Professor, University of Connecticut School of Medicine  
Farmington, CT, 06032,  
USA

**Staci R. Stevens, MA**  
Founder, Exercise Physiologist  
*Workwell Foundation is a fiscally sponsored program of United Charitable*  
P.O. Box 1435  
Ripon, CA 95366  
USA

**Dr. Alan R. Light, Ph.D.**  
Professor  
Depts. of Anesthesiology and Neurobiology and Anatomy  
3C 444 SOM  
University of Utah  
30N 1900 E.  
Salt Lake City, UT 84132

**Lucinda Bateman, MD**  
Chief Medical Director  
24 South 1100 East, Suite 205  
Salt Lake City, Utah 84102  
P 801.359.7400 | F 801.359.7404  
lbateman@batemanhornecenter.org

**Maureen R. Hanson**  
Liberty Hyde Bailey Professor  
Director, Cornell University Center for Energizing Neuroimmune Disease  
Ithaca, NY, USA

**Joyce Ferrone,**  
FNP-BC Nurse Practitioner  
24 South 1100 East, Suite 205  
Salt Lake City, Utah 84102, USA

**Benjamin H. Natelson, MD**  
Director, Pain & Fatigue Study Center  
Professor of Neurology  
Icahn School of Medicine at Mount Sinai  
New York, NY 10029, USA

**Peter C. Rowe, MD**  
Professor of Pediatrics  
Johns Hopkins University School of Medicine  
Baltimore, MD 21287  
USA

## CANADA

### **Alain Moreau PhD**

Director / Directeur

Interdisciplinary Canadian Collaborative Myalgic Encephalomyelitis Research Network (ICanCME)

Full Professor

Department of Stomatology, Faculty of Dentistry

Department of Biochemistry and Molecular Medicine, Faculty of Medicine

Université de Montréal

Scientific Director

Viscogliosi Laboratory in Molecular Genetics of Musculoskeletal Diseases

Sainte-Justine University Hospital Research Center,

3175 Cote-Ste-Catherine Road, Montreal, Qc, H3T 1C5, Canada

### **Patrick O. McGowan, PhD**

Associate Professor Departments of Biological Sciences, Cell and Systems Biology, Psychology,  
Physiology University of Toronto SW-548,

1265 Military Trail, Toronto ON M1C1A4 Canada

[www.utoronto.ca/~pmsgowan](http://www.utoronto.ca/~pmsgowan)

Lab Twitter: @MethylNation

## NEW ZEALAND

### **Rosamund Vallings MNZM, MBBS**

Howick Health and Medical Clinic

Howick, Auckland

New Zealand

### **Lynette Hodges, PhD**

Clinical Exercise Physiologist/Senior Lecturer in Exercise Science.

School of Sport, Exercise and Nutrition,

Massey University,

Private Bag 11-222

Palmerston North, New Zealand

### **Dr Eiren Sweetman**

Department of Biochemistry,

University of Otago, New Zealand

### **Don Baken PhD, PGDipClinPsych**

Registered Clinical Psychologist

Research Coordinator

Massey University

New Zealand

## AUSTRALIEN

### **Sonya Marshall-Gradisnik**

Co- Director National Centre for Neuroimmunology and Emerging Diseases

Professor Immunology, Menzies Health Institute Queensland,

Gold Coast campus,

Griffith University, QLD 4222,

### **Neil R. McGregor BDS, MDS, PhD<sup>5</sup>**

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<sup>5</sup> Post-exertional malaise is associated with changes in glycolysis and acetylation in ME/CFS patients. These changes are consistent with a hypo-acetylation state and are likely to significantly alter histone acetylation and the actions of

Clin. Assoc. Prof. University of Melbourne  
Adj. Prof. Victoria University

**Professor Donald R Staines**

National Centre for Neuroimmunology and Emerging Diseases  
Griffith University

**Dr Brett A. Lidbury, Ph.D. FFSc (RCPA)**

Associate Professor, The National Centre for Epidemiology and Population Health, RSPH,  
College of Health and Medicine,  
The Australian National University  
Canberra ACT 2601 Australia.  
W: <http://nceph.anu.edu.au/about-us/people/brett-lidbury>  
T: 02-6125 7875

**Paul Fisher**

Professor of Microbiology,  
La Trobe University,  
VIC 3086,

**Leighton Barnden**

Medical scientist,  
National Centre for Neuroimmunology and Emerging Diseases,  
Menzies Health Institute Queensland, Griffith University

