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**Final Global Conference Common strategy of research of ME/CFS**

**Book of abstracts**

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**Epidemiology of ME/CFS in Europe: past, present and future**

Fernando Estévez-López1, Kathleen Mudie2, Luis Nacul2, Jesús Castro-Marrero3, Xia Wang4, Inger Johanne Bakken5, Andrejs Ivanovs6, Nuno Sepúlveda7,8, Elin B Strand9, Joanna Slomko10, Pavel Zalewski10, Derek Pheby11, Jose Alegre3, Carmen Scheibenbogen12, Evelina Shikova-Lekova13, Lorenzo Lorusso14, Enrica Capelli15, Slobodan Sekulic16, Modra Murovska17\*, Eliana Lacerda2\*

1 Department of Child and Adolescent Psychiatry/Psychology, Erasmus MC University Medical Center, The Netherlands

2 Department of Clinical Research, Faculty of Infectious & Tropical Disease, London School of Hygiene & Tropical Medicine, UK

3 CFS/ME Unit, Vall d’Hebron University Hospital, Universitat Autònoma de Barcelona, Spain 4 Norwich Medical School, University of East Anglia, UK

5 Centre for Fertility and Health (CeFH), Norwegian Institute of Public Health, Norway

6 Statistics Unit, Riga Stradins University, Latvia

7 Department of Infection Biology, Faculty of Infectious & Tropical Diseases, London School of Hygiene & Tropical Medicine, UK

8 Centre of Statistics and its Applications, University of Lisbon, Portugal

9 National Advisory Unit on CFS/ME, Oslo University Hospital Norway

10 Department of Hygiene, Epidemiology and Ergonomy, Uniwersytet Mikolaja Kopernika Collegium Medicum, Poland

11 Faculty of Health and Society, Buckinghamshire New University, High Wycombe, UK

12 Institute for Medical Immunology, Charité-Universitätsmedizin Berlin, Germany

13 Department of Virology, National Center of Infectious and Parasitic Diseases, Bulgaria

14 Neurology Department, ASST-Lecco, Italy

15 Department of Earth and Environmental Sciences and Centre for Health Technologies, University of Pavia, Italy

16 Department of Neurology, Medical Faculty Novi Sad, University of Novi Sad, Serbia

17 Institute of Microbiology and Virology, Riga Stradins University, Latvia \* EL and MM contributed equally.

E-mail: [f.estevez-lopez@erasmusmc.nl](mailto:f.estevez-lopez@erasmusmc.nl)

In this keynote lecture, an overview of the epidemiology of ME/CFS in Europe will be provided. The aims of the lecture will be:

I. To summarise previous findings on the prevalence and incidence of ME/CFS in European countries (past).

Rationale: Previous systematic reviews on the prevalence and incidence of ME/CFS included studies from many parts of the world [1–4]. However, these previous reviews were conducted more than five years ago and either did not report the incidence of ME/CFS or did not include children or adolescents. Also, by having different inclusion criteria regarding the case definition of ME/CFS, previous reviews yielded highly variable and non-comparable findings. Thus, the EUROMENE working group 1, which focuses on epidemiology, led a systematic review to estimate the prevalence and incidence of ME/CFS in Europe [5].

II. To present and discuss the preliminary set of recommendations for standardised data collection for epidemiological research of ME/CFS in Europe (present).

Rationale: Currently, there is no single validated tool to measure all the different aspects of ME/CFS. Most researchers use a combination of various tools, without any real standardization, making it difficult to compare data and to replicate findings across studies. The issue of variability has prompted researchers from EUROMENE to consider the critical data that should be collected and to make recommendations that will facilitate consistency in methodologies and interpretability of results. Led by the EUROMENE working group 1, a multidisciplinary team of epidemiologists, clinicians, statisticians, and researchers have provided preliminary recommendations to guide data acquisition for ME/CFS research, which will ultimately improve epidemiological research. In order to ensure scalability of the suggested assessments, including applicability in population-based studies, most of them are based on self-reports. In addition to questionnaires and when circumstances (both resources and needs) allow it, additional objective measurements are suggested in order to obtain a more comprehensive picture of ME/CFS. A discussion about this set of recommendations will be carried out.

III. To suggest future perspectives for epidemiological research of ME/CFS in Europe (future).

Rationale: It will be discussed how to implement the developments of EUROMENE (e.g., set of recommendations for standardised data collection for epidemiological research of ME/CFS in Europe) in order to overcome the current caveats in the field.

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**Investigating the availability of data on ME/CFS patients in Latvia**

Diana Araja1, Uldis Berkis1, Andrejs Ivanovs1, Asja Lunga1, Modra Murovska1

1Rīga Stradiņš University, Latvia

E-mail: Diana.Araja@rsu.lv

Research is performed in framework of COST (European Cooperation in Science and Technology) Action 15111 EUROMENE (European Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) Research Network) to investigate the availability of data on ME/CFS patients in Latvia. There are no Europe-wide prevalence data, but it is assumed that

more than two million people suffer by ME/CFS in Europe. The prevalence in developed countries appears to be within the range of 0.2–1 %, but this is dependent on case definition

and criteria used by general practitioners (GP) and specialists to recognise ME/CFS. In accordance with the data from the Latvian Centre for Disease Prevention and Control (CDPC)

and The National Health Service (NHS) of Latvia, the patient-related data are classified by ICD-10 code G93.3 (Postviral fatigue syndrome), R53 (Malaise and fatigue) and B94.8 (Sequelae of other specified infectious and parasitic diseases). CDCP data from primary care

indicated that approximately 700 patients had ICD-10 code G93.3 assigned, while there were

approximately 15,000 with ICD-10 code R53, and about 70 with code B94.8. In total, these constitute about 0.8 % of the Latvian population, which is considerably higher than the prevalence found in other comparable populations. Therefore, it is likely, though unconfirmed, that the category R53 includes a great many patients with illnesses other than ME/CFS. Category G93.3, by contrast, looks like a significant underestimate of the true population prevalence. A study was undertaken in Latvia to explore to what extent GPs manage ME/CFS disease. Data received by the GPs survey, with 91 responders, show that 13 responders use Fukuda definition and criteria, and mostly ICD-10 code R53 (Malaise and fatigue) is used by GPs to denote a diagnosis. GPs participated in the survey confirm that there are many undiagnosed patients, and the total number of CFS patients in their practices could be more than 10,000 patients. As a total number of GPs operated in Latvia currently is 1,340 practitioners, the received data demonstrate that the distinction between ICD-10 used diagnosis codes for ME/CFS is not clear. This produces inaccurate data on the true number of ME/CFS patients. Completive, in Latvia the patient-related data are dispersed between categories of G93.3, R53 and B94.8 of ICD-10, so the epidemiological data show the considerably higher prevalence of ME/CFS than found in other comparable populations. The situation may be supported by the intended implementation in 2022 of ICD-11, in which it is proposed to list “Post-viral fatigue syndrome” in Chapter 08 (Diseases of the nervous system). Additionally, the disease register would be required for disease management, as the ME/CFS patients’ registries could facilitate the work of GPs, establish patients’ pathways and improve disease monitoring.

**Diagnostic criteria for Myalgic Encephalomyelitis or Chronic Fatigue Syndrome (ME/CFS) – Recommendations from the EUROMENE’s Clinical Working Group**

Eliana Mattos Lacerda1, Ruud Vermeulen2, Jerome Authier3, Luis Nacul1,4,Carmen Sheibenbogen5, Jean-Dominique de Korwin6, Uta Behrends7, Patricia Grabowski8, Jose Alegre Martin9, Anne-Marit Mengshoel10, Ingrid Hellang11, Henrik Nielsen12, Jonas Berquist13, Pawel Zalewski14, Jesus Castro-Marrero9, Fernando Estévez-López15, Modra Murovska16

1London School of Hygiene & Tropical Medicine, United Kingdom;

2CVS/ME Medisch Centrum, Netherlands;

3Paris Est-Creteil University, France;

4BC Women’s Hospital, Canada;

5Institute of Medical Immunology, Charité, Germany

6University of Lorraine and Internal Medicine and Clinical Immunology Department, Nancy University Hospital, France;

7Technical University of Munich, Germany;

8Institute for Medical Immunology, Charite´-Universita¨tsmedizin Berlin, Berlin, Germany;

9CFS/ME Unit, Vall d’Hebron University Hospital, Universitat Autònoma de Barcelona, Spain;

10Department of Health Sciences, Institute of Health and Society, University of Oslo, Norway;

11Norwegian National Advisory Unit on CFS/ME, Division of Pediatrics, Rikshospitalet, Oslo University Hospital, Norway;

12Privat Hospitalet Danmark, Charlottenlund, Denmark;

13Uppsala Universitet, Sweden;

14Department of Hygiene, Epidemiology, Ergonomy and Postgraduate Education Ludwik Rydygier Collegium Medicum in Bydgoszcz, Nicolaus Copernicus University in Toruń, Poland;

15Department of Clinical Research, Faculty of Infectious and Tropical Diseases, London School of Hygiene & Tropical Medicine, United Kingdom;

16Riga Stradiņš University, Latvia

E-mail: Eliana.Lacerda@lshtm.ac.uk

**Introduction:** The European Network on Myalgic Encephalomyelitis or Chronic fatigue syndrome (EUROMENE), aims to address the challenges related this disease, such as unknown aetiology, clinical variability, lack of diagnostic biomarkers, limited treatment options, and high associated economic burden. The network is organised into distinct working groups. The Clinical Working Group was set to survey and consider the existing procedures for diagnosis, management of symptoms and therapeutic approaches; and, to recommend a set of standardised procedures for the care of those with ME/CFS. The initial survey on clinical criteria used in European countries to diagnose ME/CFS [1] showed a paucity of standards and lack of integration of guidelines in European countries.

**Aim:** The aim of the study is to examine the main diagnostic criteria for ME/CFS, and to develop guidelines for standardising and optimising clinical diagnoses at both clinical and research settings.

**Methods:** The Clinical Working Group used a pragmatic strategy, working at face-to-face meetings complemented by remote communications to agree on key documents on clinical

definitions of ME/CFS, and existing studies/guidelines for clinical assessments and care used

in Europe and internationally. These documents were considered taking into account the WG members’ experiences and expertise, for the recommended guidelines.

**Results:** The group agreed that the Institute of Medicine (currently, National Academy of Medicine) criteria [2] and the Canadian Consensus Criteria [3] should be recommended for diagnosing adults, in primary care and secondary care/research settings, respectively. The paediatric population should be assessed recommendations from Rowe et al [4], **Conclusions:** Standardised procedures for ME/CFS clinical diagnosis and patient subgrouping

can improve the clinical care and management of symptoms, while maximising research efforts for specific biomarker(s) finding and therapeutic approaches.

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