

COST Action CA1511 Core Group

Modra Murovska, Eliana Lacerda, Uldis Berķis

WG 1 - Jesus Castro-Marrero (Spain)

WG 2 - Carmen Scheibenbogen (Germany)

WG 3 - Derek Pheby (UK)

WG 4 - Elin Bolle Strand (Norway)

WG 5 - Evelina Shikova-Lekova (Bulgaria),

WG 6 - Lorenzo Lorusso (Italy)

STSM coordination – Els Tobbacq (Belgium)

14 countries are represented

- Denmark – **Henrik Nielsen** (Private Hospital)
- Sweden – **Jonas Blomberg** (Uppsala University)
- Belarus – **Svetlana Orlova** (The Republican Research and Practical Centre for Epidemiology and Microbiology)
- The Netherlands - **Ruud Vermeulen** (The Amsterdam Chronic Fatigue and Pain Medical Centre)
- Greece – **Pania Karnaki** (Institute of Preventive Medicine Environmental and Occupational Health)

**Report of Dr Luis Nacul on the project draft for the
Horizon 2020 «Stratified and personalized medicine
for Myalgic Encephalomyelitis/Chronic Fatigue
Syndrome: A model for the realization of a new
biomedical paradigm»**

- ✓ What we have (directions and participants),
- ✓ Information needed from participants (direction, methods, sample size etc.),
- ✓ Discussion – what should be included in the first (short version) application form and how to proceed.

WG1 on epidemiology

Chair **Jesus Castro-Marrero** (Spain),
Vice-Chair **Slobodan Sekulic** (Serbia)

- ✓ Explore of ways to collect population based data on the prevalence of ME/CFS,
- ✓ Explore of the potential of existing cohorts,
- ✓ Review the characteristics of existing clinical databases maintained by collaborating institutions,
- ✓ Survey existing epidemiological data on ME/CFS in participating countries.

WG2 on biomarkers

Chair Carmen Scheibenbogen (Germany),

Vice-Chair Enrica Capelli (Italy)

- ✓ Establish special interest groups within the network able to take fragmented research in a harmonised way,
- ✓ Survey in EU countries existing data on potential immunological biomarkers of ME/CFS (cytokine profiles, lymphocyte subsets, adjuvant use epidemiology),
- ✓ Survey in EU countries existing data on potential infection-associated biomarkers of ME/CFS (viral, bacterial and fungal infections),
- ✓ Survey in EU countries existing data on potential genetic and epigenetic biomarkers,
- ✓ Survey in EU countries existing data on neuro-imaging biomarkers.

WG3 on socio-economics

Chair Derek Pheby (UK)

- ✓ Survey in EU countries existing data on economic loss due to ME/CFS,
- ✓ Analyse existing clinical criteria guidelines in order to find-out optimal criteria set allowing excluding over-diagnostic and un-diagnostic,
- ✓ Develop approaches to calculate direct economic loss due to ME/CFS.

WG4 on clinical research enablers and diagnostic criteria

Chair Elin Bolle Strand (Norway),

Vice-Chair Jerome Authier (France)

- ✓ Survey clinical criterions used in EU countries to set-up diagnosis of ME/CFS,
- ✓ Analyse existing clinical criterions guidelines in order to find-out optimal criteria set allowing excluding over-diagnostic and un-diagnostic,
- ✓ Survey in EU countries existing data on neurological picture of ME/CFS (including association with similar diseases and symptoms, like fibromyalgia),
- ✓ Analyse the used ME/CFS treatment and its efficacy/safety in order to find-out optimal treatment approaches lowering severity of clinical course.

WG5 on conferences, seminars, training schools

Chair **Evelina Shikova-Lekova** (Bulgaria)

- ✓ Where and who will organize seminars,
- ✓ Where and who will organize training schools,
- ✓ Selection of invited speakers,
- ✓ Selection of conferences to participate,
- ✓ Questionnaire to select the participants

WG6 on dissemination and exploitation, patient involvement, digitalisation

Chair Lorenzo Lorusso (Italy),

Vice-Chair Anne Marit Mengshoel (Norway)

- ✓ Create project webpage,
- ✓ Survey of existing small/medium-sized enterprises (SMEs) in the pharmaceutical, biotechnology and ICT industries in each participating country in order to develop collaborative research.

STSM coordination - U.Berķis (Latvia)

(6 visits during first year)

- ✓ Develop questionnaire to select candidates for training events,
- ✓ Information on STSM candidates,
- ✓ Information on the host institutions.

Reports of the WG Chairs – outcome from the Work Group meetings

- ✓ What is done, the current situation,
- ✓ Identified problems,
- ✓ What should be done – the perspective work plans for the next period and realization approaches,
- ✓ Approval of short - term visits' plan.

**Information on the participation in the
12th International IACFS/ME Research and Clinical
Conference: Emerging Science and Clinical Care
October 27-30, 2016, , Fort Lauderdale, Florida USA**

**European network on myalgic encephalomyelitis/
chronic fatigue syndrome (EUROMENE)**

Eliana Lacerda, M.D., Ph.D., Assistant Professor, London School
of Hygiene & Tropical Medicine

Lunch Panel

Special Interest Groups: International Research Networks

(David Patrick, Ph.D., Moderator

Professor and Director School of Population and Public Health
University of British Columbia, Canada)

Other actualities

- ✓ Final discussion on the project draft for the Horizon 2020 «Stratified and personalized medicine for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: A model for the realization of a new biomedical paradigm», Dr Luis Nacul, Dr Eliana Lacerda,
- ✓ Discussion and other actual questions (including local resources for ME/CFS research),
- ✓ Concluding remarks.