

**European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome
COST Action - CA15111**

Core Group meeting, Work Group No 1, No 3 and No 6 meeting

27th June 2019

Ibis Warszawa Centrum – Hostel Warszawa Centrum

Aleja Solodarnosci 165, Warsaw, Poland

AGENDA

AGENDA	
26th June 2019	
19.00 – 21.00	Official dinner
27th June 2019	
<i>Core Group meeting</i>	
09.00 - 09.10	Welcome & Organization Pawel Zalewski , Local Meeting Chair Modra Murovska , Action Chair
09.10 – 11.00	Participants: Chair – Modra Murovska Vice-chair – Eliana Lacerda Grant holder - Uldis Berķis WG 1 Epidemiology – Fernando Estévez-López WG 2 Biomarkers – Carmen Scheibenbogen WG 3 Socio-Economics – Derek Pheby WG 4 Clinical Research – Jerome Authier (France) WG 5 Conferences, seminars, training schools – Evelina Shikova-Lekova WG 6 Dissemination and exploitation, patient involvement, digitalisation – Lorenzo Lorusso STSM coordinator – Magdalena Budisteanu Modra Murovska <ul style="list-style-type: none"> - Progress Report/Current situation - Necessary activities till next meeting in November, 2019 - Core group discussions
11.00-12.00	<i>Lunch</i>
12.00-18.00	<i>WG1 on epidemiology meeting</i> Chaired by Fernando Estévez-López <ol style="list-style-type: none"> 1. Prevalence and incidence of ME/CFS in Europe: Systematic Review. (Fernando Estévez-López) 2. Protocols for biobanking in ME/CFS in Europe: biobanks creation, management and maintenance. (Kate Mudie) 3. Evaluating ME/CFS phenotype: recommendations for standardised methodology across European countries (report synchronised by Epidemiology, Clinical, Biomarkers and Clinical Research working groups). (Fernando Estévez-López)

	<p>4. Common ethical and legal framework for ME/CFS biobanking in Europe. (Kate Mudie and Fernando Estévez-López)</p> <p>5. Final remarks. (Kate Mudie and Fernando Estévez-López)</p>
12.00-18.00	<p><i>WG3 on socio-economics meeting</i> Chaired by Derek Pheby</p> <ol style="list-style-type: none"> 1. Welcome 2. Apologies for absence 3. Minutes of the previous meeting 4. Matters arising 5. Papers in preparation – update and discussion of way forward: <ul style="list-style-type: none"> - State-of-the-art paper (from Deliverable 15) (Derek Pheby), - Common consensus protocol (from Deliverable 16) (Derek Pheby), - Analysis of socio-economic data in the UK ME/CFS Biobank database (Rachael Hunter), - Latvian studies (disease register, patient-reported outcomes, etc) (Diāna Arāja, Uldis Berķis), - Replication of Italian study in France (Jean-Dominic de Korwin), - Economics of ME/CFS in Ireland (John Cullinan), - EUROMENE experience in Italy: health policy implication (Elena Brenna, Lara Gitto), - Other suggestions. 6. Deliverable 17 - Guidelines for health policy makers on prevention of adverse health and economic impacts due to ME/CFS <ul style="list-style-type: none"> - Contribution of comprehensive literature searches to development of a prevention model for ME/CFS – proposed STSM (Dominic Trepel, Xia Wang-Steverding), - Discussion of way forward – preparation of plan. 7. Any other business <p>Date of next meeting (if any)</p>
12.00-18.00	<p><i>WG6 on dissemination and exploitation, patient involvement, digitalisation</i> Chaired by Lorenzo Lorusso</p> <ol style="list-style-type: none"> 1) Stakeholder involvement, the question regarding SMEs, (L.Lorusso) 2) Information on open calls on EU level, could be Horizon and all others – responsibility for that (how will be responsible for information collection and placing on the web site), (L.Lorusso) 3) Booklet – may by to the end of CA15111 we should prepare something bigger that you have prepared now – some booklet, (L.Lorusso) 4) Spreading EUROMENE activities via TV and magazines, (L.Lorusso)
17.30 -18.00	Summary by WG leaders and Chair – Closing remarks