COST action CA15111

European Network on Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

Minutes of the 27.06.2019

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

Warsaw, Poland

CA15111 MC Chair: Modra Murovska
Local Meeting Chair: Pawel Zalewski

Welcome: Pawel Zalewski, Local Meeting Chair

Core Group meeting
Participants: Modra Murovska, Fernando Estévez López, Derek Pheby, Jérôme Authier, Evelina Shikova-Lekova, Lorenzo Lorusso, Uldis Berkis.

Modra Murovska (*Prezentation_MM_Warsaw_June_Fin*)

1. ***Goals of GP4 01/05/2019 – 30/04/2020:***

   a) **Aim/Primary objective (GAPG1):** Promote multidisciplinarity in ME/CFS research and foster a full chain of translational research to further develop much-needed treatment and prevention strategies for improvement of patients' quality of life. Develop strategies to collect population-based data on the prevalence of ME/CFS, develop common protocols for biobank creation in each participating country and propose a draft of common ethics framework. Promote synchronisation of biomarker panels and interpretation, and evaluate digitalisation and big data capabilities, coordinate efforts to determine the social impact of ME/CFS and to appraise the economic damage from the disease. Develop common strategy protocol for ME/CFS diagnosis, protocol and guidelines for ME/CFS subgroups detection according to the presence of symptoms and potential biomarkers´ variety. Facilitate involvement of relative stakeholders, ECIs and clinicians in WG activities.
   b) **Secondary objective 1 (GAPG2):** Develop strategies to collect population-based data on the prevalence of ME/CFS, including standardized procedures with pilot studies in selected locations, using postal questionnaires, telephone interviews or face to face interviews, and develop a geographical mapping of ME/CFS epidemiology involving correlations with other mapped information. Review existing facilities for the storage of tissue samples in participating centres to identify the nature and purposes of biological samples collected and methods used, in order to make recommendations for the development of a network-wide facility, circulate the review results among the network. Propose a draft of common ethics framework.
   c) **Secondary objective 2 (GAPG3)**: Develop panel to allow synergistic use of individual biomarker depositories towards a common biomarker factory, supporting digitalisation in biomarker deployment and big data role in ME/CFS research. Promote synchronisation of biomarker panels and interpretation, evaluate digitalisation and big data capabilities, discuss and analyse the existing data on biomarkers usable for laboratory and objective clinical diagnostic of ME/CFS.

Explore digitalisation and big data for the coordination of a roadmap towards personalised healthcare for ME/CFS.

d) **Secondary objective 3 (GAPG4):** Coordinate efforts to determine the social impact of ME/CFS and to appraise the economic damage from the disease. Compare and/or perform assessment of a theory, model, methodology, technology or technique. Exchange opinion with other health economists' associations and optimise models of prevention in health aspects.

e) **Secondary objective 4 (GAPG5):** Investigate care practices pointed out to disparities in diagnosis and treatment across EU. Develop common strategy protocol for ME/CFS diagnosis, protocol and guidelines for ME/CFS subgroups detection according to the presence of symptoms and potential biomarkers variety, including recommendations for clinical and research purposes. Develop synchronised guidelines for ME/CFS symptom management and relief (non-pharmacological and pharmacological).

f) **Secondary objective 5 (GAPG6):** Attract financial actors to the ME/CFS research area, facilitate commercialisation of existing intellectual property in the area, and foster support to SMEs. Establish special interest groups within the network and develop research proposals in response to future research program calls. Activate the promotion of ME/CFS as a research priority at European and national levels to multiply the funding sources available for large-scale funding necessary for this major societal challenge. Organize final global conference "Common strategy on research of ME/CFS". Organize STSMs, accomplish them and monitor results. Increase PhD students and ECIs activity in ITC (grant applications for participating in international conferences/congresses).

g) **Secondary objective 6 (GAPG7):** Establish the web platform with stakeholder and patient involvement, foster knowledge exchange via webpage. Facilitate the participation in common research projects providing information on open calls on EU level, and develop research proposals in response to research programme calls. Facilitate further research via the harmonisation efforts of infrastructure and other specific research in respect of topics which, where appropriate, will be the subject of specific proposals by special interest groups in response to further calls under H2020.

2. ***Information on GP4 progress - June 27, 2019:***

A. **WG tasks;**
B. **Deliverables 11-17:**

- **Deliverable 11** - Evaluation scales for assessment of neurological symptoms associated with ME/CFS and usable in diagnostic – ***30 November 2018 WG2 → WG4;***
- **Deliverable 12** - Common strategy protocol for ME/CFS diagnosis: synchronisation between centres, research component integration - ***31 December 2018 → WG4;***
- **Deliverable 13** - Protocol and guidelines for ME/CFS subgroups detection (stratification) according to the presence of symptoms and subject to potential biomarkers variation - ***30 April 2019 WG4;***
- **Deliverable 14** - Collaborative research project on ME/CFS based on synergy with other initiatives and resources integration - ***31 May 2019 → WG6;***

- **Deliverable 15** - Synchronised proposal for guidelines for management/treatment of ME/CFS: accommodating the existing and emerging therapies **-** ***31 December 2019*** **→ WG4;**
- **Deliverable 16 -** Program book/abstract book and overview of final global conference and conclusions **-** ***28 February 2020*** **→ WG6;**
- **Deliverable 17 -** Guidelines for health policy makers on prevention losses due to ME/CFS in health and economy aspects in Europe **-** ***31 March 2020*** **→ WG3.**

C. **Meetings:**

- **Warsaw, Poland, June 27, 2019;**
- **MC/WG2, WG4 and WG5 meeting on synchronization – Berlin, Germany, 20/11/2019- 21/11/2019:** In the MC meeting the current situation of GP4 – immplemented measures and planned measures – will be discussed. Each WG leader will present the acheved results corresponding to the GP4 plan. The organization and planning of the final global conference "Common strategy on research of ME/CFS" will be discussed. WG2 will discuss and analyse the existing data on biomarkers usable for laboratory and objective clinical diagnostic of ME/CFS, how to explore digitalisation and big data for the coordination of a roadmap towards personalised healthcare for ME/CFS. Protocol and guidelines for ME/CFS subgroups detection (stratification) according to the presence of symptoms and subject to potential biomarkers variation will be discussed. WG4 will discuss on (I) Common strategy protocol for ME/CFS diagnosis; (II) Protocol and guidelines for ME/CFS subgroups detection according to the presence of symptoms and potential biomarkers variety; and (III) Synchronised guidelines for management/treatment of ME/CFS. EUROMENE recommendations for the diagnosis, the investigations (specialized clinical testing such as neuropsychological evaluation, lab tests including biology, electrophysiology, neuroimaging), treatment and care organization will be produced, with writing an article to be published in an international journal. In WG5 meeting drafting of the contents of the final global conference "Common strategy on research of ME/CFS" will be discussed as well as other organizer issues. Current situation with STSMs and ITC Conference grants will be discussed. The meetings will be followed by 1st International meeting on CFS and Chronic Fatigue in Cancer and Autoimmunity, Berlin, November 21-22, 2019. The idea is to collaborate and exchange with researchers and clinicians working on fatigue in cancer and AID and to benefit from their networks and contacts with industry.
- **Final global conference "Common strategy on research of ME/CFS" and MC meeting, 12/03/2020 – 13/03/2020, Riga, Latvia.** Outputs: Conference program; program book/abstract book and overview of final global conference. The collaboration resulting from this Action will strengthen the already existing collaborations of several partners and lead to new interdisciplinary exchanges on topics which currently are disadvantaged by absent or low level communication. This Action will provide the opportunity to expand collaborations by the provision of meetings and trainings. As a result, the establishment of new contacts is

expected with teams working in other disciplines or using different methodologies.

D. Planned publications:

- Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): Investigating care practices pointed out to disparities in diagnosis and treament across European Union (20/11/2019), PLoS One;
- Scoping review about: Effects of non-pharmacologica intervention and ME/CFS patients'experiences of participation in such interventions (31/12/2019), PLoS One or Medicia MDPI;
- Cognitive impairment in ME/CFS (25/06/2019), Frontiers or PLoS One or another open access journal;
- Review on functional studies and rutine laboratory assays which may aid in the diagnosis and differential diagnosis of ME/CFS (20/01/2020), Translational Medicine or PLoS One or another open access journal;
- Summary of evaluated socio-economic direct and indirect costs caused by ME/CFS in Europe (25/06/2019), Frontiers.

E. Presentations – ITC Conference Grants:

- **Dr Diana Araja (Latvia).** *Medication preferences of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) patients.* **79th FIP World Congress of Pharmacy and Pharmaceutical Sciences 2019 , 22-26 September, 2019, Abu Dhabi, United Arab Emirates** (Poster presentation).
- **Mr Tiago Domingues (Portugal).** *Analysis of serological data towards a better understanding of the aetiology of ME/CFS.* **40th Annual Conference of the International Society for Clinical Biostatistics, 14-16 July, 2019, Leuven, Belgium** (Poster presentation)**.**

F. STSMs

- **Dr Natasa Hinic (Serbija).** *Practical approach in a herpes-, papilloma- and polyoma diagnostic as infection-associated biomarkers of ME/CFS.* 12-19 August, 2019. STSM to National Center of Infectious and Parasitic Diseases**, Bulgaria (Prof Evelina Shikova-Lekova**).
- **Dr Stefania Diaconu (Romania).** *Sleep medicine*. 9-21 September, 2019, Paris East-Creteil University, Paris, **France (Prof François Jérôme Authier).**
- **Dr Francisco Westermeier (Austria).** *Application of multivariate statistical methods to identify subgroups of ME/CFS patients*. 18 August-1 September, 2019 , London School of Hygiene and Tropical Medicine (LSHTM), **UK (Dr Nuno Sepúlveda).**

Discussion and outcome of the CG meeting:

a) In **CG** meeting the current satus of the project realization was discussed in order to identify still existing gaps and to mobilize the efforts to overcome them. One

of the main qestions discussed was the possibilities to develop collaborative research projects on ME/CFS based on synergy with other initiatives.

b) **WG1** will discuss on strategies to collect population-based data on the prevalence of ME/CFS in order to develop a geographical mapping of ME/CFS epidemiology involving correlations with other mapped information. A draft of common ethics framework regarding collection and storage of tissue samples will be discussed.
c) **WG3** will discuss on determined social impact of ME/CFS and prepared manuscript on the topic. The collected data on the economic damage from the disease will be discassed to prepare manuscript and Guidelines for health policy makers on prevention losses due to ME/CFS in health and economy aspects in Europe.
d) **WG6** will discuss on collaborative research project on ME/CFS based on synergy with other initiatives and resources integration, on interest of SMEs and patient organizations. The qestion how to improve dissemination of Activity results will be discussed.

Work Group No 1 meeting

Participants: F.Estévez-López, M.Murovska, U.Berķis, D.Pheby, J.Authier, E.Shikova-Lekova, L.Lorusso, A.Ivanovs, K.Mudie, N.Sepúlveda, P.Zalewski, X.Wang-Staverding, E.Brenna, J.Cullinan, L.Gitto, D.Arāja, J.De Korwin, A.Lunga, A.M.Mensghoel, G.Vianello

The assessment of progress of the WG-1 was briefly discussed.
F.Estévez-López showed his gratitude to the members of the WG1 for their contribution towards the general goals, tasks, milestones and deliverables stated in the Memorandum of Understanding.

1) **Evaluating ME/CFS phenotype: recommendations for standardised methodology across European countries,** delivered by F.Estévez-López

This presentation resulted from a report to be synchronised by Epidemiology, Clinical, Biomarkers and Clinical Research working groups. All the attendees of the meeting joined in this first presentation.

F.Estévez-López started the presentation acknowledging that these guidelines were led by Kate Mudie, Eliana Lacerda, Luis Nacul and himself. Overall, the attendees were satisfied by the work. They provided feedback about considering the inclusion of additional tools (e.g., the Beck Depression Inventory-II was suggested by P.Zalewski and the Mini-Mental State Examination was suggested by L.Lorusso) and adding more details into the protocol (e.g., how to perform the measurement of blood pressure was discussed by N.Sepúlveda). Also, the inclusion of additional comorbidities such as migraines/headaches was suggested by A.M.Mensghoel. The greatest concern raised the time, concentration and energy required to fill out the suggested battery of questionnaires given the disease burden in the patients. In this context, the use of short version of the instruments (e.g., the brief PEM developed by Professor Leonard A. Jason) was suggested by P.Zalewski. Additionally, J.Cullinan agreed on listening the thoughts of Irish patients with ME/CFS. All the attendees agreed on providing additional written feed

***2*) Protocols for biobanking in ME/CFS in Europe: biobanks creation, management and maintenance**.

After the first presentation, the meeting was separated in two different rooms: one room for the WG1 and WG6 meeting and another room for the WG3 meeting.

Chaired by Dr Estévez-López, led by K.Mudie.
Participants: M.Murovska, L.Lorusso, A.Ivanovs, N.Sepúlveda, P. Zalewski, A. M. Mensghoel, G.Vianello.

Dr Mudie presented the protocols already developed by the CureME group (led by Dr E.Lacerda and Dr L.Nacul, UK). After the presentation, similarly to the meeting in London, important concerns emerged about the feasibility of establishing an European biobank on ME/CFS. Thereby, the attendees agreed on developing guidelines on the minimum of biological samples to be collected in ME/CFS in Europe. This suggested collection of biological samples should be feasible for all the EUROMENE participating countries. To reach a general consensus, a form will be developed to be filled out by the representative of each country. The attendees agreed on providing such information within two weeks after the query that will be made by Dr Mudie.

2) 3rd presentation: Prevalence and incidence of ME/CFS in Europe: Systematic Review

The presentation was delivered by Dr Estévez-López who provided an updated on the ongoing work. The amendments (and rationale) to the protocol of the EUROMENE systematic review on the prevalence and incidence of myalgic encephalomyelitis/chronic fatigue syndrome in Europe were presented. These amendments are publicly available at: http://www.euromene.eu/workinggroups/20190604protocol-amendments_prevalence- me-cfs.pdf

The results of implementing these amendments were presented. As a sample of the results, figure 1 presents the flowchart.

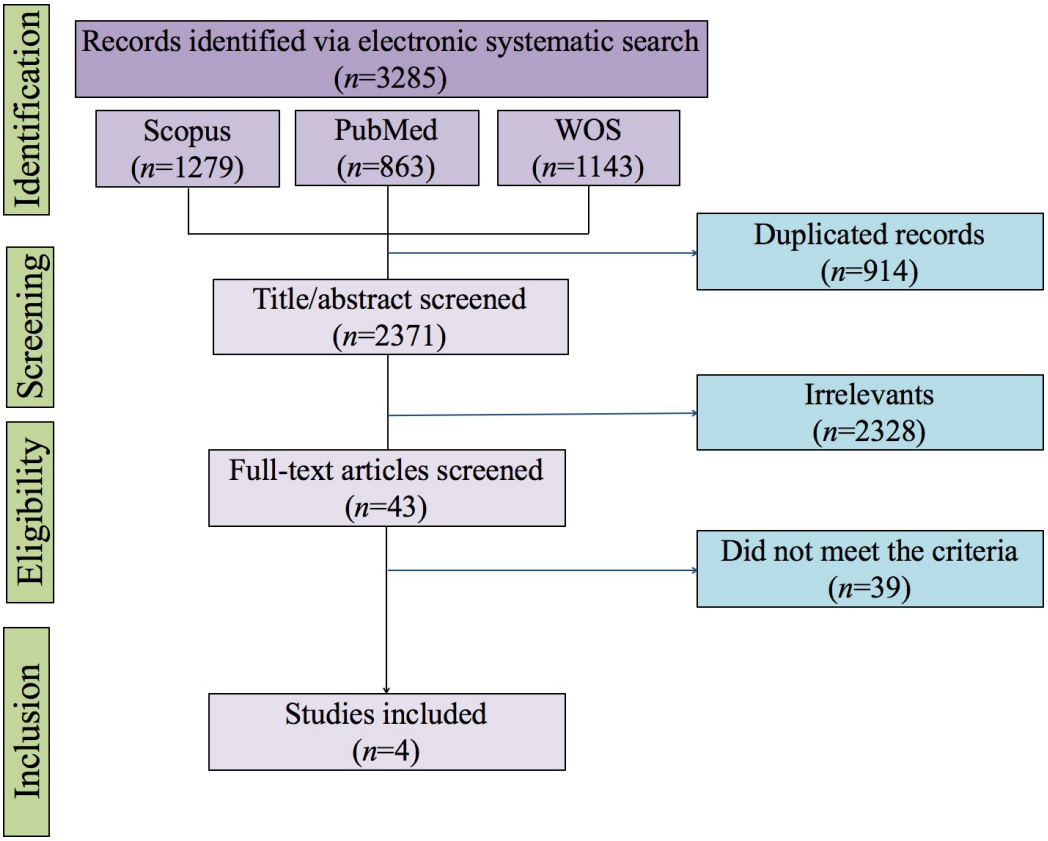

Figure 1. Flowchart of the systematic review on the prevalence and incidence of Myalgic Encephalomyelitis/Chronic Fatigue Syndrome in Europe.

The results of this work were discussed. It was agreed provided detailed information on the result section about the reasons to exclude several publications (e.g., those in which the ME/CFS diagnosis was self-reported by participants) in order to highlight the common caveat of the current state-of-the-art in the field. Collectively, the attendees agreed on the need of this study to highlight the value of investigating the prevalence and incidence of ME/CFS in Europe, which is currently unknown.

As an additional work, N.Sepúlveda proposed to estimate the prevalence and incidence of ME/CFS in Europe indirectly by using data of the prevalence and incidence of autoimmune diseases. He also proposed the inclusion of non-European data in the systematic review in order to increase the impact of this work. The idea was appraised as meaningful and he agreed on shared more information by email in order to reach a decision on whether such a work is feasible under the aegis of the EUROMENE.

3) 4th presentation: Common ethical and legal framework for ME/CFS biobanking in Europe

The contents were only informally discussed. Dr Estévez-López let the attendees know that a similar work had been already performed: hSERN, link: https://www.researchgate.net/publication/289201924_hSERN_A_tool_to_help_researchers_with_the_legal_requirements_of_cross-border_exchange_of_biological_material. Although the information is not publicly accessible (due to budget restrictions), the developers of the hSERN kindly shared a sample of information for importing and exporting samples in Germany, Spain and the UK. Therefore, to have information on ethical and legal framework for ME/CFS biobanking in Europe, EUROMENE members advised to use hSERN.

Work Group No 3 on socio economics meeting

Participants: Diana Araja, Jerome Authier, Uldis Berkis, Elenka Brenna, John Cullinan, Lara Gitto, Jean-Dominique de Korwin, Asja Lunga, Derek Pheby (chair), Xia Wang

Apologies for absence: Dyfrig Hughes, Rachael Hunter, Dominic Trepel

1. The Minutes of the meeting on 12th/13th September were agreed.
There were no matters arising.

2. Work in Progress

   i. *State-of-the-art* (Deliverable 15) and *Common consensus protocol* (Deliverable 16). It was agreed that DP would prepare a first draft of a paper for publication based on these two deliverables, and would circulate it to the Working Group [ACTION: DP]

   ii. *Analysis of socio-economic data in the UK ME/CFS Biobank database.* Rachael Hunter, despite being unable to attend the meeting, had circulated a draft paper to the group. She was concerned that the outcome was very similar to that of a paper already published by Kingdon et al. (also circulated), and wondered whether there was another angle that could be followed in order to produce something more distinctive. The group concluded that there would be merit in a comparative analysis of data pertaining to severely affected and mild/moderately affected people, as these were separately categorised in the UKMEB database, and this an analysis that Kingdon et al had not done. [ACTION: DP to email Rachael re outcome of discussion]

   iii. *Studies in progress in Latvia, Italy, France and Ireland*. Diana Araja gave a presentation regarding the work undertaken in Latvia. Two surveys have been undertaken, of GPs and patients respectively. The patients' survey, of 300 patients, based on the Italian survey, was carried out in the period December 2018 to February 2019. The current report itemises the preliminary results. Major symptoms were recorded, and basis of diagnosis. Fewer than 5% of cases were recorded as 'postviral fatigue syndrome' (i.e. ICD-10 code G93.3). 18.8% were

recorded as 'malaise and fatigue' (ICD-10 code R53), and fewer than 5% as 'chronic fatigue, unspecified' (R53.82). In the vast majority of cases (75%) the diagnostic category was stated to be 'sequelae of other specified infectious and parasitic diseases' (B94.8). The study also recorded the subjects' own views on the causes of their disease, and on factors which might affect its severity. An example was given of a typical respondent, who was female, aged forty, married, with two children, highly educated, and with an income of €500/month per household member. Monthly personal expenditure on medicine and health care services to mitigate the effects of the disease was €20 or less per month for 80% of respondents. 17.2% spent €21-50/month, while 1.8% spent €51-100/month, and 1% more than €100/month. Among patients being supported by their GPs, 72% were receiving prescription medicines, 56% used over-the-counter medicines, and 42% food supplements. Among those without GP support, 47% used over-the-counter medicines, and 49% food supplements. The overall modal reported value for health-related quality of life, on a scale of 1 to 10, was 9 before illness, and 6 during illness. For individual specific aspects of health-related quality of life (on the same scale), modal values during illness were as follows: usual activities 5, self-care 3, mobility 3, emotional state 1, physical state 1.

Two poster presentations were made at the recent Science Week at Riga Stradins University (1,2). The next steps include further data analysis, specification of topics for joint publications, with identification of suitable publications, determination of time scales, and preparation of publications, and preparation of guidelines for general practitioners and information for patients.

1. *Araja D, Pheby D, Hunter R, Brenna E, Gitto L, Berkis U, Lunga A, Ivanovs A, Murovska M. Patient reported outcomes in evaluation of socio-economic impact of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) to Society.*
2. *Araja D, Brenna E, Pheby D, Berkis U, Lunga A, Murovska M. Disease register for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) as an opportunity to encourage the integrated care of patients.*

Elenka Brenna reported on the work undertaken in Italy, and its implications for health policy. She reported that the estimated economic burden of ME/CFS in Europe was €32 billion. Initially, a literature review had been undertaken, and the results published. The results were difficult to interpret, because of a lack of consensus regarding case definition, diagnosis, and treatment. Cost elememts were complex and heterogeneous, including not only direct health and social care costs, but also productivity costs and hidden costs such as informal care and intangibles related to lowere quality of life. An empirical study was undertaken involving 108 adult patients from Northern Italy. The questionnaire based study sought general information about the patients, clinical histories, and the impact of the illness on daily living. Quality of life was assessed using EuroQol-5D. Average QoL score diminished from 90.3 before the onset of the disease to 34.6 during the previous year, a reduction of more than 55 due to the disease. Probit regression was used to create three models, taking into account, respectively, (1) patient characteristics and clinical history, (2) symptoms, self-assessed severity, and impact on quality of life, and (3) the impact of therapy. The impact of the disease on quality of life underlined the importance of costing care givers' time and costs in any evaluation of the economic impact of ME/CFS. Policy implications included the need to invest in clinical research to develop effective therapies, in order to minimise the

impact of the disease on quality of life and the economic burden associated with it. The next stages of the work will be to repeat it using a larger and geographically more dispersed group of patients in Italy, and to coordinate the work with that undertaken in Latvia and France.

Jean-Dominic de Korwin reported on the intended replication of Italian study in France. It was agreed that these projects had many common features, despite taking place in very different jurisdictions, All emphasised quality of life, and had a need to incorporate care costs, and to reflect societal and individual costs. An intended outcome would be an investigative and analytical tool capable of utilisation throughout Europe, in order to help generate the comparable data previously identified as being required to make an evaluation of the economic impact of ME/CFS throughout Europe. John Cullinan reported on work he was undertaking with the patient organisation in Ireland, which would be on similar lines. At the moment, he was engaged on a qualitative phase of this work, involving focus groups, and this could also be combined with the work in Latvia, Italy and France, as an input into Deliverable 17, with a view to subsequent publication in an academic journal. The quantitative phase of this work would not be completed until the end of 2020 at the earliest, which would obviously not be in time for inclusion in the results of this COST Action. [ACTION: DA, EB, LG J-D de K, and JC to work together on this]

iv. *Deliverable 17 - Guidelines for health policy makers on prevention of adverse health and economic impacts due to ME/CFS.*
It was agreed (as above) that one element of the deliverable would be a report based on the work being undertaken in Italy, France, Latvia and Ireland. Another element would be the construction of a prevention model. Xia Wang and Dominic Trepel are working on this. This will be based on an examination of risk factors, and DP has sent a literature search on the role of risk factors in ME/CFS to XW and DT. Diagnostic delay appears to be the most important risk factor associated with the development of severe ME/CFS, and DT proposes to construct a Markov model, on the basis of the literature review, and jointly with XW [ACTION: DT, XW].

v. There were no <u>other suggestions</u> for work to be undertaken.

3. The next scheduled meeting will be the end of project conference in Riga on 12th/13th March 2020. There will be a Management Committee meeting in Berlin on November 20th. There is no meeting scheduled for WG3 on that date, but it is hoped that some members of WG3 who are also members of the MC will be able to meet then. There may be a need for a telephone conference to review progress sometime before Christmas.

Work Group No 6 on dissemination and exploitation, patient involvement, digitalisation meeting meeting

Participants: *Lorenzo Lorusso, Anne Marit Mengshoel, Evelina Shikova-Lekova, Giampietro Vianello, Paweł Zalewski*

1) ***Stakeholder involvement, the question*** **regarding SMEs**

Dr Lorenzo Lorusso presented on behalf of WG6 a brief note on a Italian SMSe involvement in Euromene, MAGI Lab located in Lombardy Region, with interest on a research regarding a genetic sequencing on twins and/or young patients affected by CFS/ME. Some participants (N.Sepulveda, J.De Korwin) asked the number of candidate patients for this study. At the moment only two families with a total of 5 members we recruited. They are not sufficient for this kind of study but using recent genetic analysis of biological samples could be useful. A common European Ethical consensus is necessary for this kind of research. We proposed with this project a collaboration with other Euromene members. By this year we're going to proceed for this study. A research on other European SMSe interested to participate at our Cost Action we will seek.

2) Information on open calls on EU level, could be Horizon and all others: Prof. Uldis Berkis showed the main EU Horizon 2020 calling that Euromene could participate but at the moment the EU open calls are directed to IT. Uldis encouraged to find other source of grants such national project of each country involved in Euromene.

3) A leaflet on Euromene and general information on CFS/ME has been printed in English and a digital version has been posted it on Euromene web site. Bulgarian, Italian and Spanish versions have been realized. By the end of July the leaflet will be translated in the main languages of the Euromene countries. The aim is a local circulation of the leaflet in each country involved in Euromene for its capillary diffusion regarding a major knowledge about CFS/ME among health institution, physicians and population. A booklet with details on Euromene activities is planned by to the end of CA15111.

4) Spreading EUROMENE activities: a strategy regarding the diffusion of the Euromene project in order to both grow public awareness and establish a network-wide WEB-based information platform designed to facilitate medical research into CFS/ME. Mr Vianello presented suggestions aimed at a further improvement of the Euromene website and offered advice with regard to the possible creation of social media accounts (namely Facebook, Twitter and YouTube); such an advice was grounded in considerations relative to the demographic targets of the project. Other than that, establishing an online connection with multiple business/patient associations was highlighted as a vital course of action. Finally, the advantages of featuring the group's activities in print publications were discussed.

5) Patients involvement: Dr Sławomir Kujawski on behalf of the Polish CFS/ME association.


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