



COST

EURO-EpiME survey

*A new initiative from EUROMENE
ME/CFS Epidemiology Working Group*

Jesús Castro, PhD
Barcelona, Spain



What has WG1 done so far?

◆ EURO-EpiME survey

New alternative ways about how to collect epidemiological data from EU countries

◆ RED-Cap Fatigue study

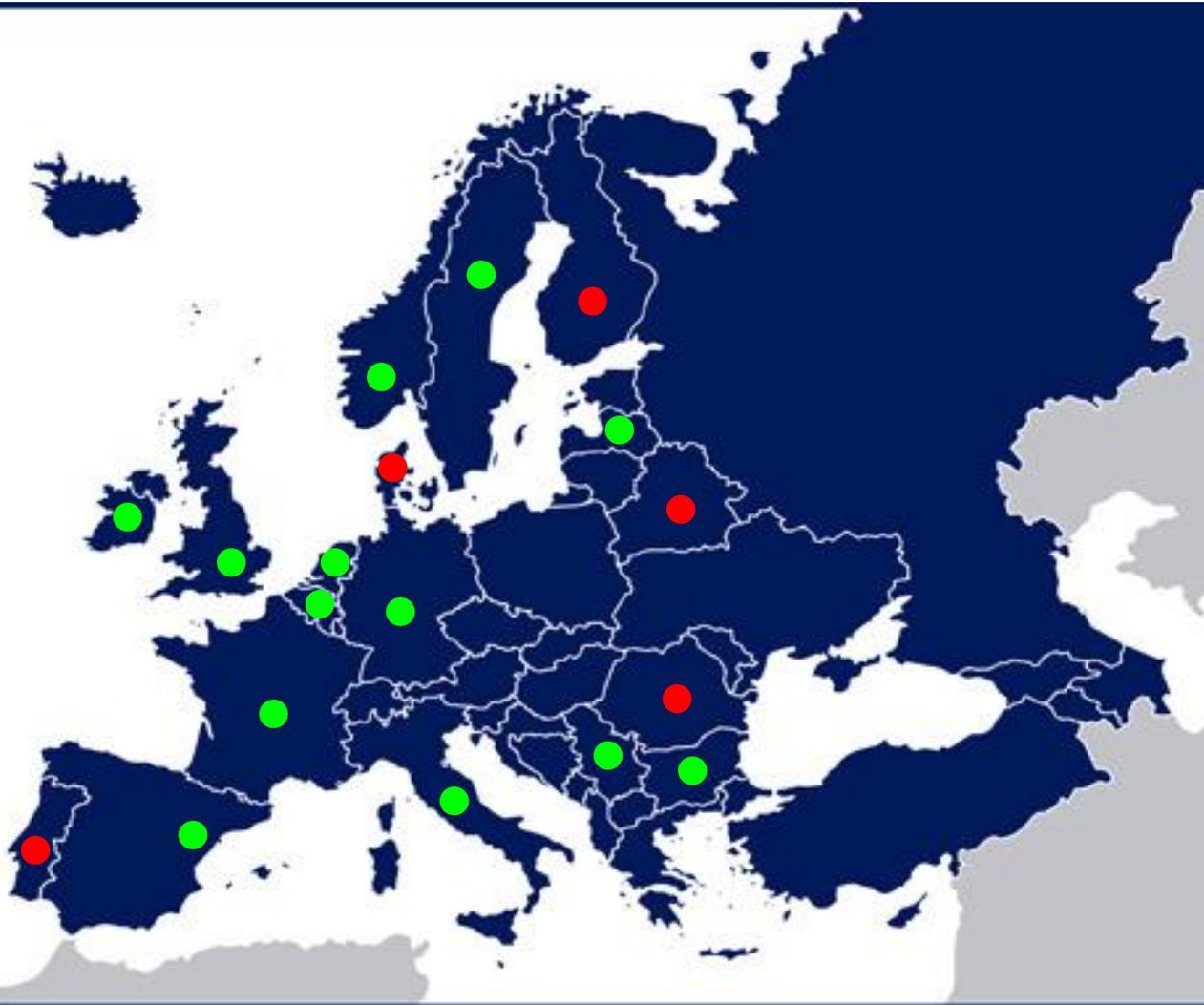
International collaboration to booster synchronization between EUROMENE WG1 & WG4

◆ Systematic literature review on the prevalence of ME/CFS across Europe

An epidemiological approach is addressed through EUROMENE ME/CFS Epidemiology WG



Availability of EURO-EpiME survey data



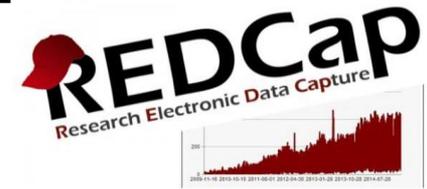
● Survey data retrieved

Bulgaria
Belgium
France
Germany
Italy
Norway
Spain
Serbia
Sweden
UK
Ireland
The Netherlands
Latvia

● Survey data no-retrieved

Belarus Romania
Finland Portugal
Denmark

What is online RED-Cap Fatigue survey?



Prof Lenny Jason & Dr Madison Sunnquitt
DePaul University - Chicago, USA



Dr Elin Strand
Oslo Univ Hospital – Oslo, Norway



Dr Jose Alegre & Dr Jesus Castro
Vall d'Hebron Univ Hospital – Barcelona, Spain

Measures

DePaul Symptom Questionnaire (DSQ)

An exploratory study evaluating the DSQ to subtyping patients with ME (2003 Canadian criteria) and CFS (1994 Fukuda definition) based on core symptom domains in a Spanish ME/CFS cohort using a factor analysis.

Short Form-36 Health Survey (SF-36)

A preliminary survey to measuring substantial activity reductions in ME/CFS cohorts. The aim is examine the relationship between certain SF-36 sub-domains and provide an accurately homogeneous measure in functioning reductions of a Spanish ME/CFS sample.

Hospital Anxiety and Depression Scale (HADS)

There is a lack of research examining the epidemiology of health anxiety/depression in ME/CFS across Europe. This preliminary study aims to determine the prevalence data for anxiety/depression in a Spanish ME/CFS cohort and comparing with other cohorts in USA & Europe.



RED-Cap Fatigue study participants

- ◆ DePaul sample
ME/CFS patients (n= 217) & HCs (n= 96)
- ◆ UK Newcastle cohort
ME/CFS subjects (n= 100)
- ◆ Oslo cohort: sample1 (n= 176)
sample 2 (n= 64)



RED-Cap Fatigue survey participants

◆ DePaul sample

ME/CFS patients (n= 217) & HCs (n= 96)

◆ UK Newcastle cohort

ME/CFS subjects (n= 100)

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HHS Public Access

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Factor Analysis of the DePaul Symptom Questionnaire: Identifying Core Domains

Leonard A. Jason¹, Madison Sunnquist¹, Abigail Brown¹, Jacob Furst¹, Marjoe Cid¹,
Jillianna Farietta¹, Bobby Kot¹, Craig Bloomer¹, Laura Nicholson¹, Yolonda Williams¹,
Rachel Jantke¹, Julia L. Newton², and Elin Bolle Strand³



RED-Cap Fatigue survey participants

- ◆ **DePaul sample**: ME/CFS patients (n= 217) & HCs (n= 96)
- ◆ **UK Newcastle cohort**: ME/CFS subjects (n= 100)
- ◆ **Oslo cohort**: sample1 (n= 176)
sample 2 (n= 64)

Barcelona cohort (ongoing)

ME/CFS subjects (n= 300)

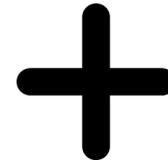
Recruitment and data collection: From Sept 2017 to Oct 2018



Key elements of systematic review (EURO-EpiME survey data)

Structured, systematic process involving several steps:

1. Formulate the question
2. Plan the review
3. Comprehensive search
4. Unbiased selection and abstraction process
5. Critical appraisal of data
6. Synthesis of data (*may include meta-analysis*)
7. Interpretation of results



All results will be addressed and discussed by Fernando Estévez (Granada, Spain)

Strategic goals to move forward on EURO-EpiME study across Europe

A new initiative of EUROMENE to booster the ME/CFS research between EU countries

Moving towards novel strategies to collect population-based epidemiological survey data on the prevalence of ME/CFS in Europe

The ME/CFS Epidemiology WG will seek to identify research gaps on ME/CFS prevalence and future priorities on risk factors across Europe

Unknown specific cause

Lacking of a 'gold standard' for clinical case criteria

ME/CFS is a real, multi-system chronic condition characterized by extreme fatigue and other symptoms that don't improve with rest and may even worsen with physical and mental exertion leading Post-Exertional Malaise

~ 4M European patients could be affected with ME/CFS

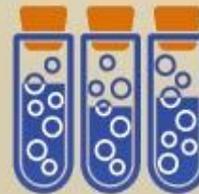
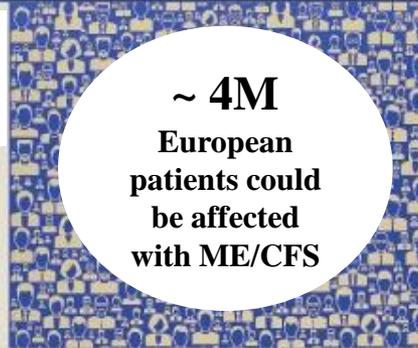
Women are affected by ME/CFS more often than men

ME/CFS affects both children/adolescents and adults

ME/CFS and autoimmunity: evidence of Rituximab trial

No clinically established lab tests exist

No universally FDA-approved drugs are available



Q & A



**May I be excused?
- my brain is full -**

