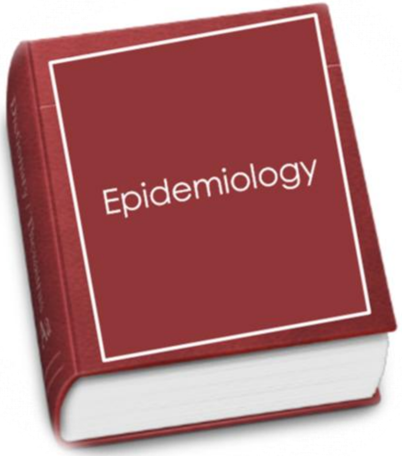
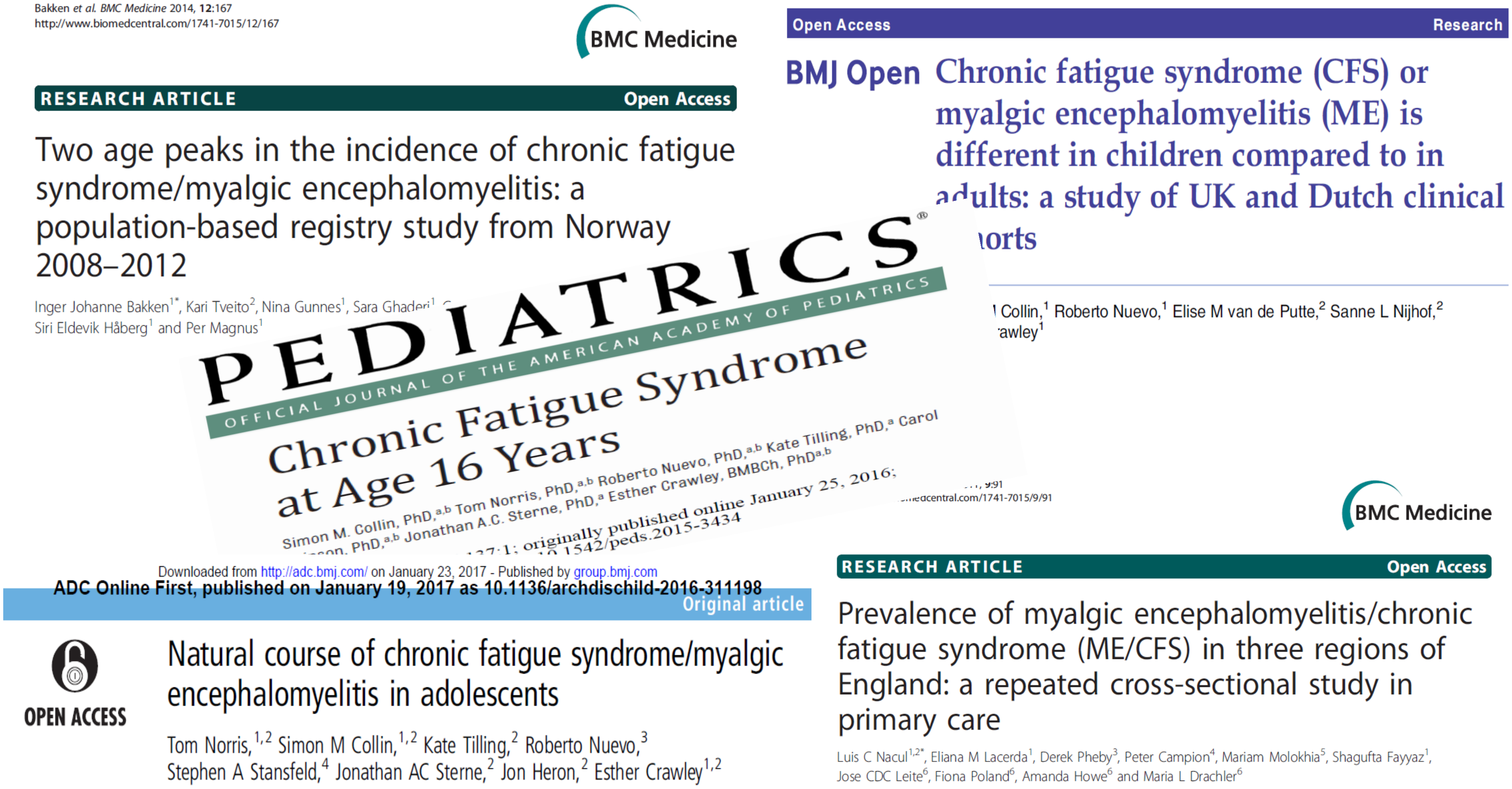


Epidemiology of ME/CFS in Europe:

where we are and where we need to go

Jesus Castro, PhD
Vall d’Hebron University Hospital
ME/CFS Unit
Barcelona, Spain

Background on ME/CFS prevalence in children/adolescents and adults



Bakken *et al. BMC Medicine* 2014, **12**:167
http://www.biomedcentral.com/1741-7015/12/167

BMC Medicine

RESEARCH ARTICLE **Open Access**

Two age peaks in the incidence of chronic fatigue syndrome/myalgic encephalomyelitis: a population-based registry study from Norway 2008–2012

Inger Johanne Bakken[1*], Kari Tveito[2], Nina Gunnes[1], Sara Ghaderi[1]
Siri Eldevik Håberg[1] and Per Magnus[1]

Open Access Research

BMJ Open

Chronic fatigue syndrome (CFS) or myalgic encephalomyelitis (ME) is different in children compared to in adults: a study of UK and Dutch clinical cohorts

Collin,[1] Roberto Nuevo,[1] Elise M van de Putte,[2] Sanne L Nijhof,[2]
rawley[1]

PEDIATRICS®

OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Chronic Fatigue Syndrome at Age 16 Years

Simon M. Collin, PhD,[a,b] Tom Norris, PhD,[a,b] Roberto Nuevo, PhD,[a,b] Kate Tilling, PhD,[a] Carol
PhD,[a,b] Jonathan A.C. Sterne, PhD,[a] Esther Crawley, BMBCh, PhD[a,b]

137:1; originally published online January 25, 2016;
1542/peds.2015-3434

, 9:91
medcentral.com/1741-7015/9/91

BMC Medicine

RESEARCH ARTICLE **Open Access**

Prevalence of myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) in three regions of England: a repeated cross-sectional study in primary care

Luis C Nacul[1,2*], Eliana M Lacerda[1], Derek Pheby[3], Peter Campion[4], Mariam Molokhia[5], Shagufta Fayyaz[1], Jose CDC Leite[6], Fiona Poland[6], Amanda Howe[6] and Maria L Drachler[6]

ADC Online First, published on January 19, 2017 as 10.1136/archdischild-2016-311198

Original article

OPEN ACCESS

Natural course of chronic fatigue syndrome/myalgic encephalomyelitis in adolescents

Tom Norris,[1,2] Simon M Collin,[1,2] Kate Tilling,[2] Roberto Nuevo,[3]
Stephen A Stansfeld,[4] Jonathan AC Sterne,[2] Jon Heron,[2] Esther Crawley[1,2]

(EUROMENE)

WG1 – Epidemiology of ME/CFS across EU countries

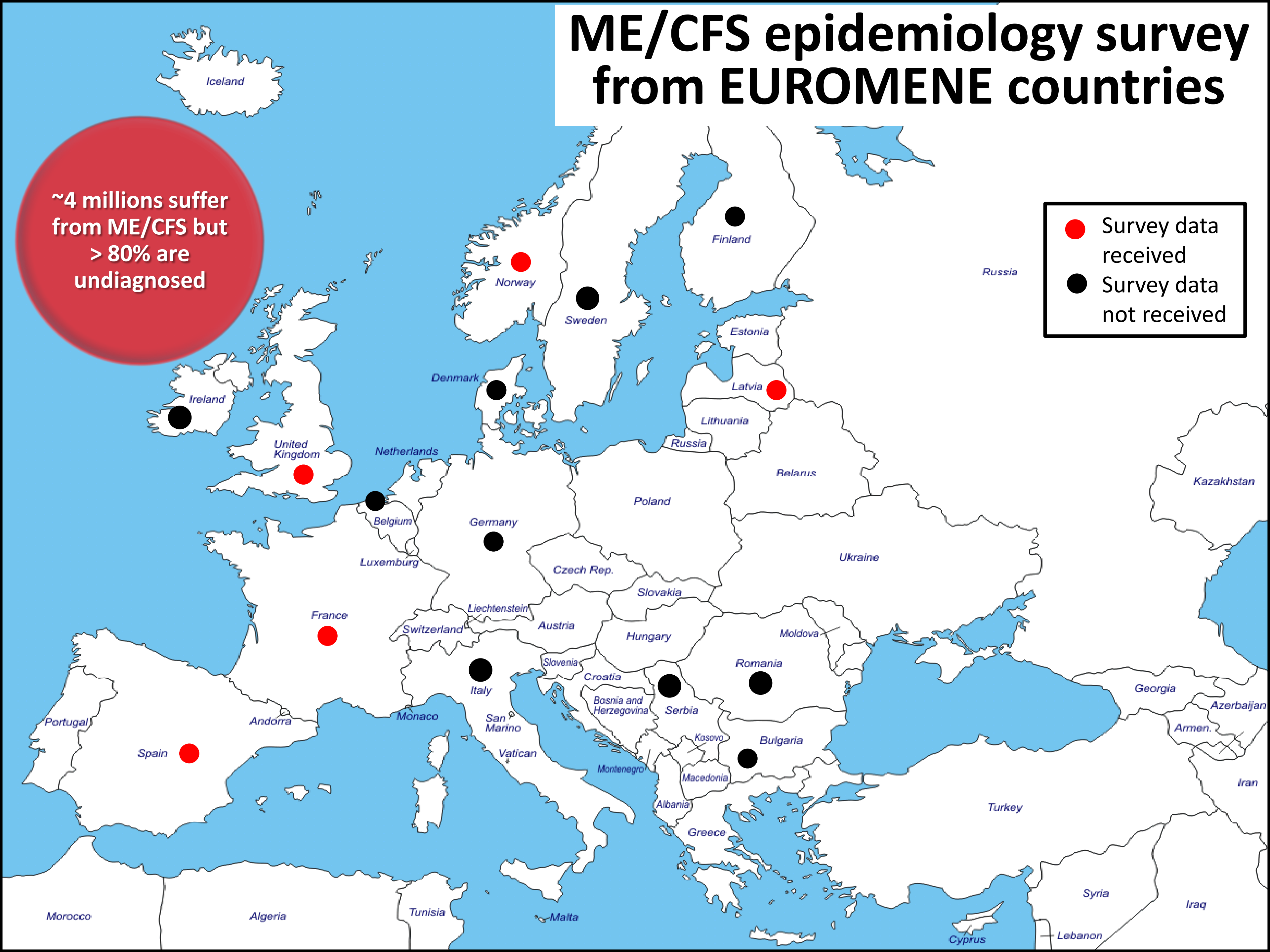
Aim: **Establishment of joint open epidemiological platform for action deliverables**

1- Document on ME/CFS prevalence in E.U. countries

2- Information via web on existing ME/CFS biobanks, usage availability and restrictions

3- Guidelines on ME/CFS biobank management and maintenance

ME/CFS epidemiology survey from EUROMENE countries



~4 millions suffer from ME/CFS but > 80% are undiagnosed

🔴 Survey data received
● Survey data not received

Existing ME/CFS biobanks in Europe via web

LONDON
SCHOOL *of*
HYGIENE
&TROPICAL
MEDICINE

The UK ME/CFS Biobank

Better recognition, less stigma, improved diagnosis and treatment

Biobank FAQs -- find out more about our team, patient selection, and future goals!

Building on feasibility studies, the UK ME/CFS Biobank project set out to establish the UK's first biobank of biological samples for research on ME/CFS. The project launched in August 2011 with the support of Action for ME, The ME Association, and ME Research UK, as well as private donations. The project is led and managed by the London School of Hygiene & Tropical Medicine.

Samples are processed and securely stored at the state-of-the-art University College London/Royal Free Hospital Biobank (UCL/RFH Biobank) in London.

Support the UK ME/CFS Biobank Big Give Campaign --

The Big Give Christmas Challenge continues through to Wed., Dec. 17th, 5 PM GMT!

The ME Association is generously hosting the challenge on our behalf.

As of Dec. 11th, we have raised £32,282 -- WOW! Thank you so much for your support!

Can you please help us reach our target of £100,000 to help ensure the sustainability of the UK ME/CFS Biobank?

Oslo
University Hospital

ME/CFS-centre

The ME-Registry in Norway

ME-registeret

@MEregisteret

ULLEVÅL
universitetssykehus

- Pasient
- Aktuelt
- Fagfolk
- Om Ullevål
- Medier
- Jobbe på Ullevål

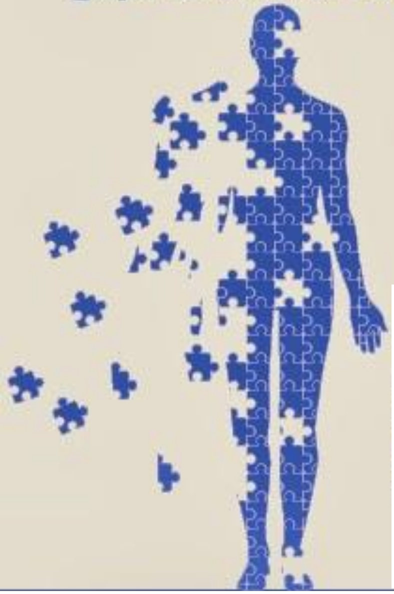
VELKOMMEN TIL ME/CFS-SENTERET

Landscape on prevalence of ME/CFS across E.U. countries

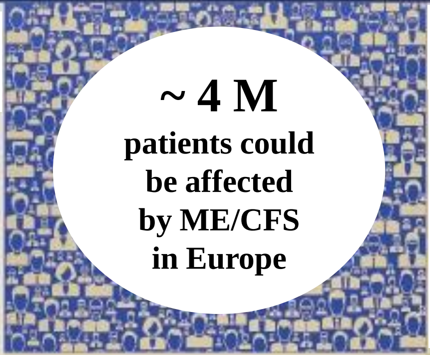
EUROMENE pathways to ME/CFS research in Europe

Moving towards novel strategies to collect population-based data on the ME/CFS prevalence

The EUROMENE will seek to identify research gaps on ME/CFS and future research priorities across E.U.



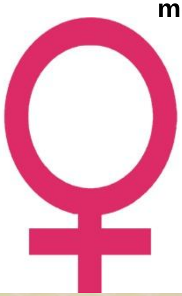
ME/CFS is a complex, multisystem, chronic medical condition characterized by extreme fatigue and other symptoms that do not improve with rest and may even worsen with physical and mental activity.
No known specific cause



~ 4 M
patients could be affected by ME/CFS in Europe

No clinically established lab tests exist

Women are affected by ME/CFS more often than men



ME/CFS affects both children/adolescents (aged 16-18 yrs) and adults (aged 30-50 yrs)

No universally FDA-approved drugs are available

EUROPEAN COOPERATION
IN SCIENCE AND TECHNOLOGY