ME/CFS IN THE NORDIC COUNTRIES

Status of Health Care and Research and Suggestions for Joint Actions and Policies

REPORT ON THE NORDIC ME NETWORK (EMEA NORDIC) SURVEY AND CONFERENCE 8.11.2021

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ACKNOWLEDGEMENTS

The Medical Association of ME/CFS in Finland thanks our Nordic partner organisations and the expert speakers and participants for their input and time.

Special thanks to Richard Simpson, chairman of the European ME Alliance for invaluable help with chairing the meeting and setting up the digital event. We thank him for kindly supporting our project and for providing the Nordic ME associations with a European framework.

We dedicate this report to Ellen V. Piro, *grande dame* of ME patient advocacy and founding member of the Norwegian ME Association, one of the oldest and most important patient organizations for ME/CFS in the world. She retired last year, but we hope to carry the torch.

Thanks to everyone who read and commented on the draft.

The conference and report were made possible thanks to financial support from William Thurings stiftelse and the Nordic Welfare Centre.

William Thurings stiftelse

Nordens
välfärdscenter

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Cover illustration: WWW.VECTEEZY.COM

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EXECUTIVE SUMMARY

Background

ME/CFS (*myalgic encephalomyelitis/chronic fatigue syndrome*) is a little-known but "serious and debilitating somatic condition that can cause significant impairment and disability" (IOM 2015). An estimated 55,000-220,000 persons in the Nordic region have ME/CFS, and the number is likely to double in the wake of the COVID-19 pandemic, along with related disease burden and costs, which may amount to several billion euros per year in the Nordic countries only. It is critically important to take proactive measures to respond to the public health crisis in the making. For more detailed cost estimates, see page 12.

The Medical Association of ME/CFS in Finland (SLME) organized an online conference on 8 November 2021 with the purpose to assess the existing Nordic ME/CFS health care and research resources and how to put them into good use. The conference brought together 15 Nordic ME experts, including clinicians, researchers, and patient advocates from the six Nordic ME associations of the Nordic ME Network (NOMENE). The European ME Alliance was also represented. Link to the webinar: https://www.europeanmealliance.org/emea-nordic-web.shtml

Purpose

1. **Map the state of healthcare and research** on ME/CFS in the Nordic countries to gain insight into strengths and needs in terms of infrastructure, policy, and resources,
2. **Suggest joint Nordic strategies and standards** to advance improvements in guidance, clinical work, research, and education, as well as coordinate this information with the European ME Alliance.

The overall aim is to reduce inequity and improve patient care for people with ME/CFS by facilitating coordinated research and development of health and social services and optimized utilisation of Nordic resources in the field.

Methods of Data Collection

- **Survey** sent to Nordic ME Network associations before the conference
- **Expert presentations** to assess the state of current healthcare and research
- **Online workshops and discussions** during the conference and
- **Request for additional information** to participants after the conference.

Major Challenges Identified

1. **Shortage of resources directed to ME research and service provision,** which leads to suboptimal care, increased disease burden and costs.
2. **Lack of harmonized strategies and standards** regarding case definitions, diagnosis and treatment, which causes inequality and makes it difficult to collect consistent data for research and development purposes.
3. **Lack of updated medical knowledge and training**, which leads to missed and delayed diagnoses, individual suffering, and stigma.

Suggestions for Joint Actions

Since expertise and resources in the field of ME/CFS are sparse, the report stresses the need for sharing Nordic resources and developing joint actions for improved and equitable care. Actions proposed include:

- **Research:** Increased funding for high-quality biomedical ME research in accordance with Agenda 2030 goals and the EU resolution 18.6.2020. Increased research collaboration (e.g., multi-centre RCTs on promising pharmacological treatments and interdisciplinary studies involving Long COVID).
- **Education**: Introducing ME education in medical schools. Developing Nordic online modules for postgraduate medical training and continuing professional development. Establishing Nordic trainee programs and fellowships. Developing an Electronic Doctor's Handbook. Organizing international symposiums on the post-viral conditions ME and Long COVID in the Nordic region. Continuing support for patient-led initiatives such as public awareness campaigns and the Nordic "toolbox" for schools.
- **Guidelines**: Adopting more uniform and international definitions, standards of diagnosis and treatment to prevent inequality. Standardisation would also facilitate research and help monitor the development of care and services. Translating key documents such as existing national guidelines and information packages would accelerate implementation of good practices.
- **Health policy**: Adding resources for co-ordinated research, training, guidance, and development of services. Establishing a Nordic competence centre for professional consultancy and medical research on ME, Long COVID and other post-infectious conditions, as is under way in Germany.

For more detailed and complete lists of suggestions, see pages 30, 34 and 37.

Summary and Next Steps

This project is intended to be a step towards building a successful and coherent Nordic model for ME/CFS care, research, and education based on facts, evidence, and consensus. The report provides data intended to support and prompt apt responses to the severity of the problem, including investments in biomedical research and improvements in health and social services for people with post-viral conditions. It provides a roadmap for concrete action that is so urgently needed.

Disclaimer

Views and opinions expressed do not necessarily reflect the opinions of individual conference participants or organizations. The report is provided for informational purposes only and does not substitute professional medical advice.

> *"If you are a decision maker, here is what you urgently need to do:*
> *You need to bring funding for biomedical ME/CFS research up*
> *so it's on par with comparable diseases*
> *(as an example, in the US that would mean $188 million per year)*
> *[Author's comment: in the Nordic region that would mean > €13 M/year].*
> *You need to make sure there are dedicated hospital care units for ME/CFS inpatients in every city around the world. You need to establish specialist biomedical care available to all ME/CFS patients; it should be as natural as RA patients having access to a rheumatologist or cancer patients to an oncologist.*
> *You need to give ME/CFS patients a future."*
>
> Anne Örtegren,
> Swedish patient advocate, Farewell Letter 2018.

ABBREVIATIONS AND ACRONYMS

CBT	Cognitive Behavioural Therapy
CCC	Canadian Consensus Criteria
EMEA	European ME Alliance
EMECC	European ME Clinicians Council
EMERG	European ME Research Group
EUROMENE	European Network on ME/CFS
GET	Graded Exercise Therapy
GP	General Practitioner
ICC	International Consensus Criteria
IOM	Institute of Medicine aka National Academy of Medicine
LC	Post-COVID19 condition aka Long COVID (ICD-10 U09.9)
LDN	Low Dose Naltrexone
ME/CFS	Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ICD-10 G93.3)
ME	Myalgic Encephalomyelitis (used alternately with ME/CFS)
NICE	National Institute for Health and Care Excellence, UK
NIH	National Institutes of Health, USA
NMER	Norwegian ME Association (*Norges Myalgisk Encefalopati forening*)
NOMENE	Nordic ME Network
PEM	Post-exertional malaise
PANS	Pediatric Acute-Onset Neuropsychiatric Syndrome
POTS	Postural Tachycardia Syndrome
PVFS	Postviral fatigue syndrome
RME	Swedish ME Association (*Riksförbundet för ME-patienter*)
SBU	Statens beredning för medicinsk och social utvärdering
SLME	Medical Association of ME/CFS in Finland (*Suomen lääketieteellinen ME/CFS-yhdistys*)
WHO	The World Health Organization

1 INTRODUCTION

Background

The Medical Association of ME/CFS in Finland (or Suomen lääketieteellinen ME/CFS-yhdistys, hereafter: SLME) is a registered patient advocacy organization. Its target groups include the ME/CFS community of patients and caregivers as well as medical and scientific professionals and policymakers. One of its main objectives is to help establish national and international professional networks to facilitate continuing improvements in patient management and care. Towards this effect, SLME decided to organize a conference bringing together patient organizations, clinicians, and researchers from the Nordic region. The point of involving representatives from different countries with different areas of ME expertise was to add perspective to our knowledge and understanding of this serious and debilitating condition.

A Letter of Intent was signed already in September 2019. The intention was to arrange annual meetings at alternate Nordic airports beginning with Helsinki Airport on 25 March 2020, hence the working title "First Annual Nordic ME Network Airport Meeting". The physical meeting had to be postponed due to travel restrictions imposed because of the COVID-19 pandemic. The meeting was finally held as a virtual conference on 8 November 2021 with 15 participants from the 6 partner organizations of the Nordic ME Network (NOMENE) as well as their umbrella organization the European ME Alliance (EMEA). The online conference is documented on EMEA's webpage: https://www.europeanmealliance.org/emea-nordic-web.shtml

Method and Objectives

SLME conducted a small survey on the state of ME/CFS health care and research among the Nordic ME associations (Chapter 2) before the conference. The present report documents the survey results as well as presentations, workshops, and discussions held during the conference itself. Chapter 3 provides a status update on the clinical and research situation in the Nordic countries and Chapter 4 presents ideas and suggestions towards common strategies and standards.

The initiative aims at improving quality and equity of care by increasing collaboration and unifying standards between the Nordic countries when it comes to diagnosis and treatment of ME/CFS. Another aim is to support biomedical ME/CFS research and promote co-operation between research groups for optimal use of resources. There is also a need for developing common methods and standards for data collection to fill knowledge gaps. To our knowledge, this is the first Nordic ME report of this kind.

In the long run, Nordic and European ME collaboration will hopefully help advance clinical care, research, and education and lead to improvements in the treatment of patients afflicted with this severe but little-known and often stigmatising condition.

What is ME/CFS?

Myalgic Encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS), as defined by the Institute of Medicine (2015), is a "serious, chronic, complex, and multisystem disease that frequently and dramatically limits the activities of affected patients". Hereafter the abbreviations ME and ME/CFS will be used alternately to reflect varying usage in different countries and contexts. Since 1969 the WHO recognizes it as a neurological disorder, and it is currently classified under the codes G93.3 (ICD-10) and 8E49 (ICD-11) (postviral fatigue syndrome). The cause is not yet fully known, and there is no known cure.

Though poorly understood, ME/CFS is not a rare disease. According to a recent EUROMENE report, there are "probably around 3 million in the European continent living with ME/CFS" (Estévez-López et al. 2020). With an estimated prevalence rate of 0,2-0,9% applied to the Nordic population this corresponds to 55,000-240,000 Nordic citizens (Lim et al. 2020). Because the disease often begins after an infection, including infections with SARS, the number of affected is likely to increase dramatically in the wake of the COVID-19 outbreak. Predictions vary and are provisional, but even conservative estimates suggest that COVID-19 could lead to long-term sequelae resembling ME/CFS in c. 10% of the cases (WHO 2021; Walitt & Bartrum 2021; Komaroff & Bateman 2021). These estimates are confirmed by data on previous epidemics (Hickie et al. 2006; Blomberg et al. 2018).[1]

ME/CFS occurs in the most productive phases of life, the age peaks of onset being 10-19 and 30-39 years (Bakken et al. 2014). Key symptoms include pathological fatigue, sleep abnormalities, unrefreshing sleep, orthostatic intolerance, cognitive dysfunction ("brain fog"), and pain, including muscle and joint pain and headaches. The hallmark symptom is post-exertional malaise (PEM), that is, long-lasting symptom aggravation following even minor exertion. Functional capacity is significantly reduced in all areas of life (**Figure 1**).

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[1] To date (on 18 November 2021) there are over 2 million registered COVID-19 cases in the Nordic countries, which could lead to **c. 200,000 new ME cases** (118,000 in Sweden + 42,700 in Denmark + 22,900 in Norway + 17,000 in Finland + 1,574 in Iceland). [Editor's comment: On 3 March 2022 there were over 7,3 million registered COVID-19 cases in the Nordic countries].

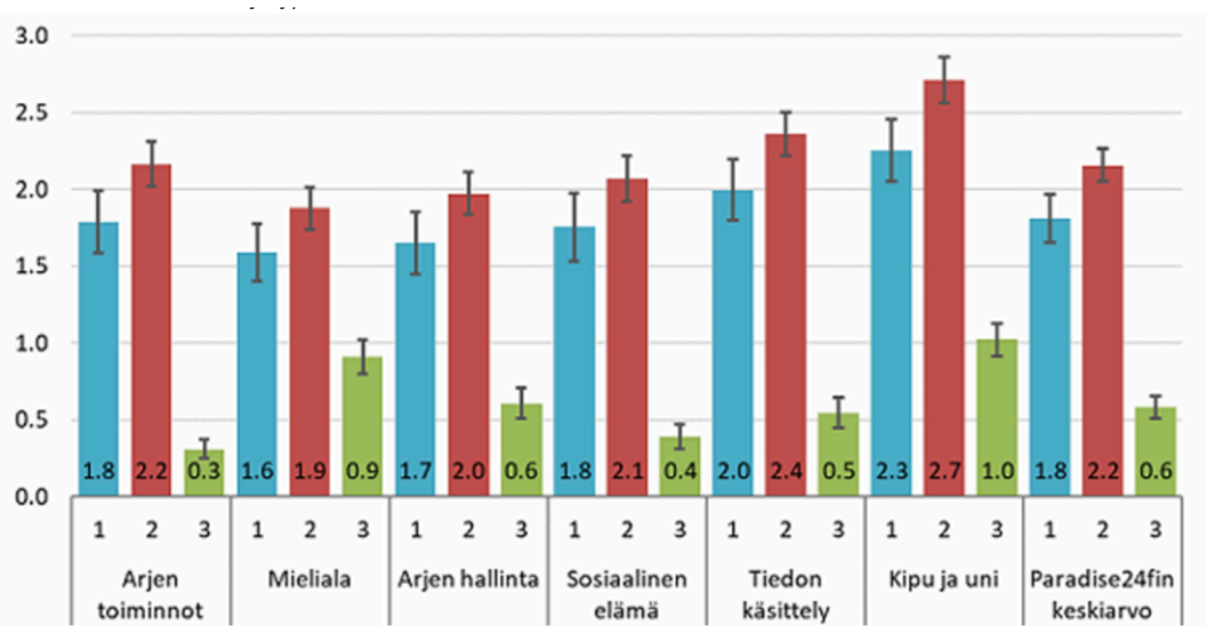

Figure 1. Working-aged people with ME/CFS experience significantly more difficulties in all areas of functioning than healthy controls. 1 = Diagnosed with ME/CFS without significant co-morbidity (n = 63), 2 = Diagnosed with ME/CFS with significant co-morbidity (n = 107), 3 = Control group (N = 139)
© Ahonen & Aranko 2019.

At least 75% are unable to work or attend school and 25% are house- or bed-bound at some point of the illness. The quality of life is significantly lower than in other chronic or disabling diseases, such as MS, cancer, depression, diabetes, epilepsy, or cystic fibrosis (**Figure 2**). The chance of full recovery in adult subjects is only 5% (Cairns & Hotopf 2005), but early diagnosis as well as symptom- and activity-management are likely to improve the outcome.

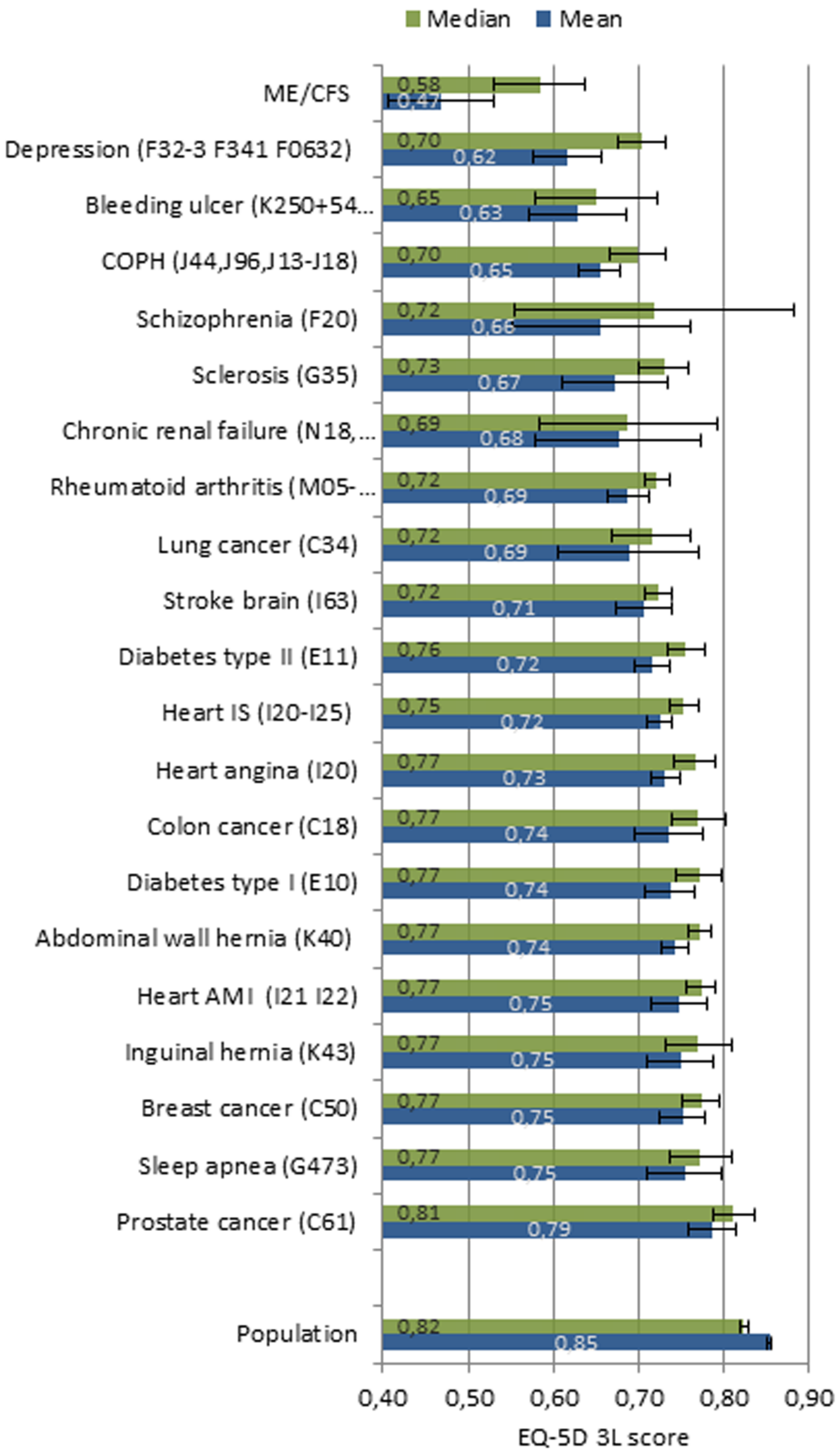

Figure 2. Health-Related Quality of Life. With permission from the author (Hvidberg et al. 2015).

Why is ME/CFS a strategic Nordic priority?

The health care expenditure related to ME/CFS in the Nordic countries can be estimated to 1,5-3,7 billion €/year, and the cost may increase with c. 2,7 billion in the wake of the ongoing pandemic.[2] And these estimates do not count indirect costs such as loss of productivity of caregivers and disability costs, nor do they consider the possible surge of cases due to omicron and later variants. According to a recent chronic disease modelling, if applied to the Nordic population, Long COVID would already have caused the loss of more than 75,000 quality-adjusted life-years (Martin 2021; STM 2022). These estimates are necessarily rough and indicative, but by any standard losses are considerable. Even a modest reduction of the losses could deliver savings of hundreds of millions of euros every year. Apt and timely diagnosis and management would improve the outcome and decrease both individual suffering and societal costs, not to mention the discovery of a biomarker and/or a cure.

Despite significant disease burden, biomedical research into ME/CFS remains flagrantly underfunded (**Figure 3**). There is little or no updated medical training on ME/CFS, and as health providers have limited knowledge, diagnosis is often missed or delayed. The average diagnostic delay last reported in Sweden is 9,5 years and up to 90% of the cases remain undiagnosed (RME 2019; IOM 2015). Those diagnosed may receive inappropriate or even harmful treatment. Access to care is limited, as there are few or no specialized ME/CFS clinics or specialists. People with ME are often stigmatised and discriminated against and failed by the welfare system. Lack of recognition and support from health and social services add to the burden of physical suffering.

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[2] A EUROMENE report estimates the annual ME related costs in Europe to 40 B € based on extrapolation from UK 2002-estimates (Pheby et al. 2021). If applied to the Nordic region with its 27,6 million inhabitants (3,7% of the European population) the Nordic equivalent amounts to c. **1,5 B €/year**. If based on a comprehensive Finnish estimate of health care expenditure (Hassel 2019), the Nordic equivalent amounts to c. **1,87-3,74 B €/year** (prevalence 0,5-1%) and the cost of additional ME cases due to COVID-19 to 2,7 B €/year (200,000*13,630€).

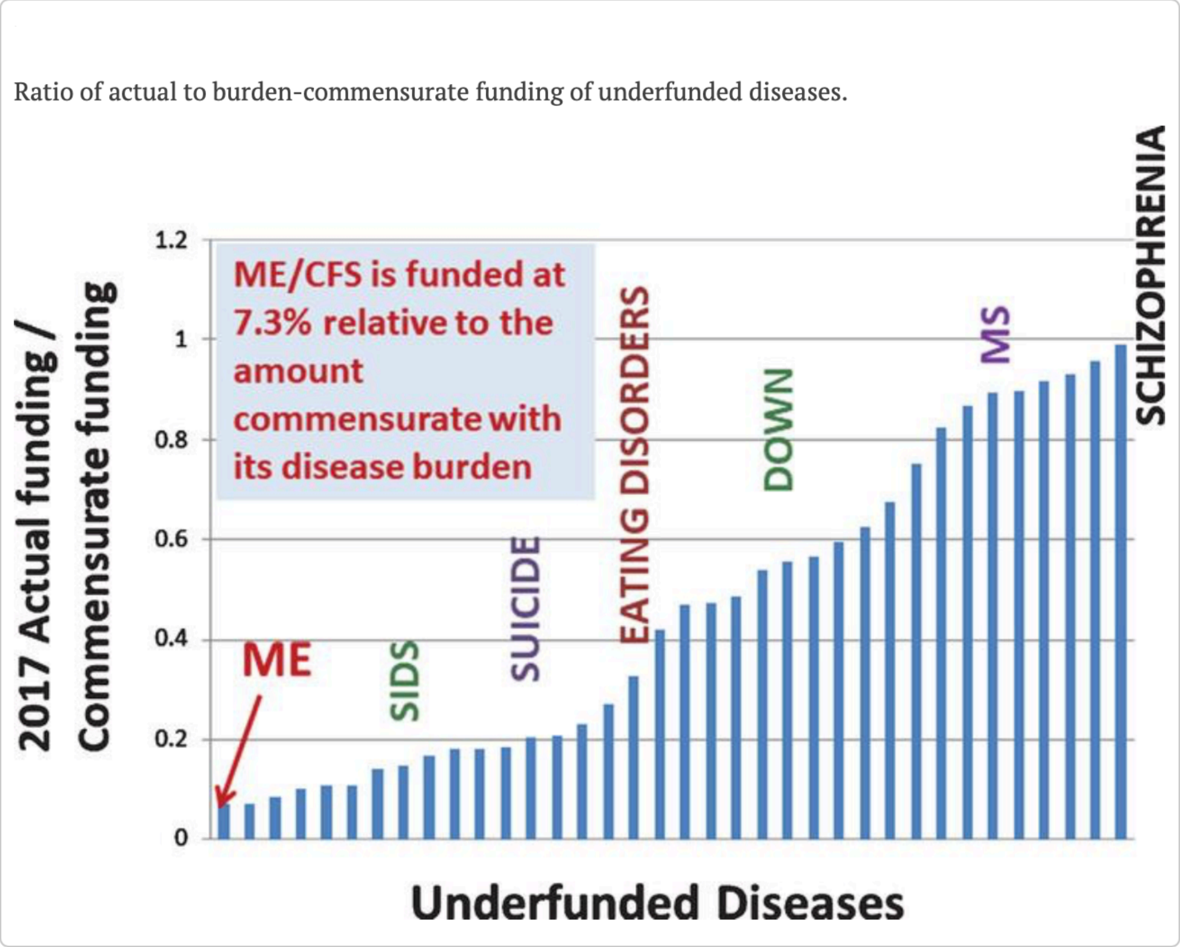

Figure 3. ME/CFS disease burden versus research funding in USA 2017. Reprinted from "Work", Vol number 2, Mirin, Arthur A., Dimmock, M. and Jason, L., "Research update: The relation between ME/CFS disease burden and research funding in the USA, Special Section: ME/CFS", pp. 277-282, Copyright 2020, with permission from IOS Press.

Actions necessary

A paradigm shift in the understanding of ME/CFS occurred in 2015 with the publication of the Institute of Medicine report, based on a systematic review of more than 9000 articles, redefining ME/CFS as a "medical – not a psychiatric or psychological – illness". While the etiology is not yet fully explored, studies show neurologic, immunologic, autonomic, and energy metabolism impairments. The governments of the USA, Australia, Canada, and Norway have since provided increased funds to stimulate biomedical research into ME/CFS.

In June 2020 the European Parliament sent an important signal in a resolution that calls on the Commission and Member States to

- allocate funding and prioritise calls for projects on **biomedical** ME research,
- increase research cooperation between Member States and
- ensure the due recognition of ME/CFS by launching information campaigns.[3]

In March 2021 the Dutch government committed to providing additional funding for ME research, commissioning a ten-year biomedical research programme funded with €28.5 million. In October 2021 the Health Department of Isle of Man reallocated resources and funding for setting up ME and Long COVID services. In November 2021, the German federal government, in its coalition agreement, promised to establish a nationwide network of competence centres and interdisciplinary outpatients to further research and secure care for long-term patients with COVID-19 and ME/CFS. These are timely examples of what can be achieved with vision and a willingness to address the challenges.

As UN Member States all Nordic countries have signed the UN Convention of rights for people with disabilities and are committed to the 2030 Agenda of Sustainable Development and its sustainable development goals, including

- good health and well-being for all (Goal 3),
- reduced inequality (Goal 10)
- peaceful and inclusive societies with access to justice for all (Goal 16) and
- partnership with exchange of knowledge and experience (Goals 17).

It is high time for the Nordic countries to take measures to counter the long-term socio-economic impact of this neglected public health crisis so to avoid further unnecessary losses.

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[3] For more information, see Petition 2020/2580(RSP)
https://www.europarl.europa.eu/doceo/document/TA-9-2020-0140_EN.html

2 NORDIC ME PATIENT ORGANIZATIONS

NOMENE / EMEA Nordic

There are six registered patient organizations specifically for ME in the Nordic countries. In 2014 these associations formed the Nordic ME Network (NOMENE) to facilitate information exchange and strengthen co-operation among the Nordic countries. All Nordic ME patient associations are also members of the European ME Alliance (EMEA), a grouping of European charities and patient organisations currently representing 17 EU countries. Therefore, NOMENE is also known as EMEA Nordic. The Nordic ME associations are shortly described below.

FINLAND (1)

SUOMEN LÄÄKETIETEELLINEN ME/CFS-YHDISTYS

(SLME)

Chair: Samuli Tani

Founded in 2017

SLME has c. 360 members.

Membership fee is optional.

Unlike most ME associations in other Nordic countries and despite notable results, SLME has not been granted state support.

The activities depend on volunteer efforts, donations and project grants.

Main activities and achievements:

-SLME arranges and participates in educational and scientific events
-Translation of major documents (IOM-report 2015, "Purple Book" 2018)
-Development of an official all-party parliamentary network for ME/CFS
-Promoted and contributed to the development of national Good Medical Practice recommendations (Duodecim 2021)
-Development of tailor-made training for experts by experience (2021)
-Initiated and hosted the NOMENE conference (8.11.2021)

Current projects:

-Distance learning robot avatar for school children in co-operation with Turku university hospital

-Translating the handbook "Pacing for People with ME" into Finnish

-Planning a pilot peer support group for Pacing in Swedish.

WWW.SLME.FI

FINLAND (2)

ME|CFS-YHDISTYS

SUOMEN ME/CFS-YHDISTYS

(SMEY)

Chair: Satu Enwald represented in the conference by board member Dr Olli Polo

Founded in 2013

SMEY has c. 300 paying members.

Main activities and achievements:

-Arranging peer-support groups

-Participating in the national Good Medical Practice recommendations (Duodecim 2021)

-Supporting members who aim to become certified experts by experience.

Current projects:

-Well-received (c.100 participants/time) monthly live stream with Dr Olli Polo

-Starting a collaboration with Tampere University Hospital pilot project service for fatigued patients.

WWW.SMEY.FI

ICELAND

ME/CFS ASSOCIATION OF ICELAND

(ME félag Íslands)

Chair: Guðrún Sæmundsdóttir

Founded in 2011

243 members (in February 2022)

Main activities and achievements:

-Producing educational animations about post-exertional malaise and life with ME (Lífið með ME)

-Co-operating with the Medical Director of Health and others from the national health sector

-Member of ÖBÌ, an umbrella organization of 41 associations of people with disabilities in Iceland

Current projects:

-Looking into the rights of ME/CFS patients with a legal expert

-Translating Dahl's pacing guide and Mayo guidelines (2021) into Icelandic

-Planning a translation of NICE guidelines 2021.

WWW.MEFELAG.IS

SWEDEN

RIKSFÖRBUNDET FÖR ME-PATIENTER (RME)

Chair: Kerstin Heiling

Founded in 1993

RME has c. 2230 paying members, 11 regional divisions and a board divided into several committees (e.g., conference, IT, communication).

Main activities and achievements:

-Has conducted two big member surveys (2009 and 2019)
-Arranges yearly ME conferences (in October)
-Meetings with Health officials and politicians
-Hosting Facebook groups for members (eg. caregivers, severely ill)
-Active on Twitter, Facebook and in other media to participate in the official ME agenda
-IMembers of *Funktionsrätt* (The Swedish Disability Rights Federation) and in this role also submitting responses to consultations from the government
-Swedish Parliamentary hearing in May 2021

Current projects:

-Working on a Swedish version of a Nordic Toolbox for schools

-Financial support from the government as of 2022.

WWW.RME.SE

NORWAY

NORGES MYALGISK ENCEFALOPATI FORENING (NMEF)

Secretary General Olav Osland,
represented in the conference by Board member Rune Hoddevik,
who replaces Ellen Piro in NOMENE as of November 2021

Founded in 1987

NMEF is probably the biggest and oldest ME patient organisation in Europe with 5600 paying members and 5 employees.

Main activities and achievements:

-Arranges an annual research conference in Oslo in November together with the Norwegian Institution for Public Health (*Folkhelseinstituttet*) and the National competence service (*Nasjonal kompetenstjenste for CFS/ME*)

-Funds research projects and awards research scholarships

-Have conducted 6 major survey studies that have influenced healthcare policies in Norway.

Current projects:

-Have been instrumental in conducting the EMEA pan-European ME Patient Survey (to be published in 2022)

-Together with the regional ME association of Rogaland NMEF have developed a "Toolbox" for schools, i.e., an information package on the special needs of children and adolescents with ME. The Toolbox consists of a booklet, animations, and lecture soon to be available in 3-4 Nordic languages online at www.meogskole.no

-Have contributed to the opening of a public treatment centre for severely afflicted ME patients with 12 beds in Røysumtunet in December 2020.

WWW.ME-FORENINGEN.NO

DENMARK

ME FORENINGEN
(MEF)

Chair: Cathrine Engsig

Founded in 1992

MEF has 1160 members (in January 2022)

Main activities and achievements:

-Have translated a range of ME information materials (ICC, PEM, POTS).
-Annual participation in a 6-day exhibition for Danish general practitioners informing them on latest ME news
-Invites doctors, physiotherapists, lawyers, and dieticians with ME knowledge to talk at member webinars
-Meetings with health officials and politicians
-Active in social and other media to participate in the official ME agenda
-Have conducted 3 big member surveys and contributed to a peer-reviewed health quality survey (Hvidberg et al. 2015)
-Before Covid-19: sending Danish doctors to the ME conferences in Norway, Sweden and England

Current projects:

-Together with the Norwegian regional ME Association of Rogaland it has published a "toolbox" with a booklet and online course for teachers for the special needs of school children and adolescents with ME/CFS.
Homepage:
https://www.meogskole.dk/

-Currently working on a new homepage funded by ME-relatives.

WWW.ME-FORENINGEN.DK

3 STATUS UPDATE ON NORDIC ME/CFS HEALTH CARE AND RESEARCH

3.1. Survey Results

*A 16-item survey was sent to the Nordic ME associations before the airport meeting that was planned to be held in March 2020. Respondents could stay anonymous, so their views are personal, and should not be taken as the official opinions of any organization. For question form and a table of responses, see Appendices **D** and **E.***

The survey identifies some strengths in the treatment of ME/CFS between the Nordic countries, but also major knowledge gaps and inconsistencies regarding fundamental issues such as treatment methods and access to care and social rights. Even nomenclature and case definitions vary between the Nordic countries. In most countries and contexts, the name "ME" as in myalgic encephalomyelitis or -encephalopathy is most commonly used, while in Finland the unfortunate interpretation "chronic **tiredness** syndrome" (*krooninen väsymysoireyhtymä*) still prevails. When it comes to treatment guidelines, only Norway and Finland have national recommendations. While most countries respect WHO classifications and use updated case definitions such as Canadian and/or International Consensus Criteria for diagnosis, the situation in Denmark is clouded with up to four sets of diagnostic criteria, including the dated Oxford (1991) and Fukuda (1994) criteria that do not require the hallmark symptom post-exertional malaise (PEM). Also, contrary to international consensus and recent recommendations and guidelines, such as EUROMENE 2021 and NICE 2021, Cognitive Behavioural Therapy and Graded Exercise Therapy are still offered as curative treatments to ME patients in Denmark. As for medical research funding and efforts, Norway leads the way. A search for "ME/CFS" project on ClinicalTrials.gov in February 2022 indicates that there are 19 recent or ongoing trials in Norway, 6 in Sweden, 4 in Finland and none in Denmark and Iceland.

Strengths

- Good infrastructure for registries and biobanks
- The WHO classification (G93.3) is *officially* respected by most Nordic health ministries and medical societies (except for the Danish Health Board and the Ministry of Social and Health Affairs in Finland, who refer to ME as a functional disorder)
- Some successful and promising ME/CFS research projects have been financed and launched, especially in Norway
- Active patient advocates and charities are making constant efforts to increase public awareness and to advance evidence-based quality science and policymaking.

Challenges

- *Knowledge gaps*:
  - No or very limited or imprecise data on prevalence, incidence, disease progression, disease burden, societal costs, etc.
  - Lack of medical ME expertise and education.
- *Inadequacies*:
  - Lack of medical ME services: the number of specialists and specialized clinics is insufficient, especially to cater for the most severely affected.
  - Lack of research (funding), especially Denmark and Finland lag behind compared to Norway and Sweden. Tellingly, it is also in these countries that ME is still treated as a functional disorder.
  - Lack of clinical guidance: most Nordic countries still have no national guidelines for diagnosis and treatment of ME/CFS.
  - Even where national guidelines exist, they are not fully implemented
- *Inequality*: flagrant discrepancies when it comes to
  - Access to public care: truly specialized ME care exists only in Norway and Sweden (with only one clinic)
  - Treatment/management: Different methods are used in different countries.
  - Social security: People with ME in all Nordic countries face discriminatory treatment and difficulties to obtain social security.

Suggestions

- All Nordic countries should develop/update and implement national ME guidance with respect to current WHO classifications and the best available evidence.

- Uniform case definitions, diagnostic and treatment methods should be adopted to prevent inequality and facilitate research on strictly defined cohorts. A recent EUROMENE report confirms the need to improve and harmonise regulations, guidance, and standards on the European level (Strand et al. 2019).
- Consistent use of registries and systemized data collection are necessary to fill in knowledge gaps and make research and quality assessments possible.
- Discrimination goes against Nordic values of equality, transparency, and the rule of law. Legislators should condemn such practice and act to reinforce legal certainty in matters of care and social benefits.

STATISTICS FROM NORDIC SURVEYS STUDIES

90% of single household with ME experience some degree of financial difficulty

70% of ME patients are registered as unemployed though being incapable of full-time work

58% do not have a regular contact in primary care

70% have difficulties to go to appointments due to poor health

74% were not taken seriously, did not receive treatment instructions

74% have gotten worse from Graded Exercise Therapy

c. **67%** do not dare/want to contact healthcare due to bad experiences

87% of the families do not receive any support from the municipality

25% of the families had problems with child protection

(Ahonen & Aranko 2019; RME 2018-19; NMEF 2016)

3.2. Presentations

Finland

Access to care

In line with the British guidelines (NICE 2021), the Finnish Good Medical Practice-recommendations (Duodecim 2021) do not define ME/CFS as a functional disorder. The WHO ICD-11 classifies ME/CFS as a *differential diagnosis* to functional disorders. Yet, Finland is reportedly one of the few member states of the European ME Network, where ME/CFS is still officially treated as a functional disorder (Cullinan et al. 2021 section 3.2.2).

Between 2007 and 2017 Unesta Sleep and Breathing Centre in Tampere run by Professor Olli Polo was the only clinic in Finland specializing in diagnosing and treating patients with ME. Since 2019 Dr Polo is working at Bragée ME/CFS Centre in Stockholm.

Tampere University Hospital has a pilot project service for "tired patients" (*väsyneen potilaan pilottihanke*).[4] It accepts referrals from all over the country, but it is difficult to get a referral and the waiting list is long. The service performs assessments of disability, which are allegedly useful and extensive, though demanding for the patients.
The pilot project does not offer any treatment, the focus being to put an end to excessive investigations when patients with ME go without diagnosis.

One of the only public treatment options for ME patients in Finland at present is the Functional Disorders Clinic at Helsinki University Hospital, which opened in April 2019.[5] The methods of the Functional Disorders Clinic have aroused controversy.[6] No audit has yet been conducted, but according to patient reports the therapies promoted by the clinic have not been helpful in ME/CFS.[7]

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[4] https://www.tays.fi/fi-fi/ohjeet/laheteohjeet_ja_konsultaatiot/vasyneen_potilaan_tutkimus_ja_laheteohje

[5] https://www.hus.fi/hoidot-ja-tutkimukset/toiminnallisten-hairioiden-hoito

[6] https://svenska.yle.fi/artikel/2021/05/06/det-ar-inget-annat-an-hjarntvatt-hus-foresprakar-kontroversiell-vard-till

[7] https://www.me-media.fi/2020/11/husn-toiminnallinen-hairio.html?m=1

Research

To our knowledge, Finland is one of the few member states of the European ME Network that has not made public investments into biomedical ME research. State funding of medical research was cut by half in 2010-2017,[8] and the negative trend continues despite the pandemic.

One of the few ongoing biomedical research projects in Finland is a small (N=30) double-blind placebo controlled clinical trial on intestinal microbiota in Tampere University Hospital (Salonen et al.).

The Finnish Association of People with Physical Disabilities (*Invalidiliitto*) are planning a first peer-reviewed national survey on ME patients including videography (Hiekkala et al.), but progress is slow due to the lack of funding.

Social security and disability allowance in Finland

A Finnish foundation (*A-klinikkasäätiö*) has conducted a quantitative patient survey, noting that "*as it is often difficult to get disability benefits on the grounds of an ME/CFS diagnosis, a patient may be left in an ambivalent situation, being unable to work, yet not granted sickness allowance*" (Ahonen & Aranko 2019, translation from the Finnish).

People with ME/CFS are not eligible for sickness allowance by The Finnish Social Insurance Institution (KELA) and insurance companies, demanding objective findings of disability. Many patients are categorized "incapacitated job seekers" (*työkyvytön työnhakija)* by the public employment and business services and may thus be subjected to inappropriate activation programs. The situation has not improved with the functional disorders approach adopted in recent years.
In 2019 alone, at least ten child protection complaints were made about families with children suffering from ME/CFS and there were at least 5 cases of forced custody of severely ill children with ME/CFS. In one of the cases, administrative court ruled that the child should be returned to its family. [9] There is a great risk of wrongful child protection measures, since social workers in Finland receive no training in ME/CFS and the condition can be confounded with school fear or behavioural problems.

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[8] https://www.diabetestutkimus.fi/files/278/Laaketiedetta_tukevien_saatioiden_selvitys_2019_valmis.pdf

[9] https://www.mtvuutiset.fi/artikkeli/harvinaista-sairautta-sairastava-tiia-13-sijoitettiin-lahes-vuodeksi-ilman-riittavaa-syyta-turhautunut-isa-lastenkodissa-tytolle-vakuutettiin-etta-han-on-terve/7933538#gs.s9s8x2

Sweden (Ass. prof. Sture Eriksson, Umeå University)

In Sweden there are c. 41,200 ME patients (estimate based on 0,4% prevalence), many without proper diagnosis (cf. MS 24,000). As for age distribution, most are middle age. Function reduction is significant.

Access to care

The pandemic revealed problems in the Swedish health care system with its complicated and bureaucratic organization. There are only two specific ME facilities: Bragée Clinic in Stockholm and a recently established clinic at Umeå University Hospital. Special pain clinics in Göteborg and Linköping ("complicated tiredness") also admit ME patients, as do a few private initiatives. There is an urgent need to improve ME services both as regards volume and quality. There is, however, reluctance to develop clinical care since no one sees it as their responsibility. According to the RME member survey 17% of the respondents had sent complaints about experienced medical care and/or neglect in primary care to the Health and Social Care Inspectorate (*IVO*). An additional 29% had wanted to file complaints but did not manage to do it.

Disability status of patients

Social security in Sweden is based on objective findings, which causes problems for people with ME. The RME survey reveals that only 4% of the ME patients have full or almost full work capacity (75-100%) when estimated by the treating physician, while the corresponding number is 41% when estimated by the Swedish Social Insurance Agency (*Försäkringskassan*). The situation is far from equitable. Many applications are refused and there are many appeals.

Children with ME

There are no special facilities for children with ME and the level of knowledge about the illness in healthcare is alarmingly low. The child welfare authorities have started custody cases, threatening to remove young ME patients from their families and in a handful of cases threats have been carried out.

Medical ME research in Sweden

- Uppsala university: Jonas Bergqvist et al., Open Medicine Foundation-supported centre with focus on advanced analysis in clinical chemistry.
- Linköping: Anders Rosén's group with focus on immune system study.
- Stockholm Bragée Clinic with focus on clinical data, clinical chemistry, and cervical instability.
- Stockholm Karolinska Institute based group with focus on clinical symptoms and clinical chemistry analysis.
- Umeå: Senior researcher engaged, but still in planning phase. Systematic biobanking initiated.

Conclusions

Clinical care: Improvement both in volume and quality urgently needed. The strategy should be based on deepened analysis.
ME research: Further development of co-operation between centres and connection needed to advance clinical care. Public funding almost non-existent.

Norway (Prof. Kristian Sommerfelt, University of Bergen)

There may be up to 40,000 ME patients in Norway (if 0,8% prevalence), many without correct diagnosis, the diagnostic delay being 4 years. There was a reported incidence peak in 2006-2008. Canadian Consensus Criteria are used for diagnosis of adults, Jason (2006) criteria for the young. There are national guidelines, but they are not always followed. The new NICE 2021 guidelines in the UK are more up to date.

Healthcare is lacking: No speciality is responsible for the care of ME patients, and there is reluctance to give an ME diagnosis, because patients look and seem fine during consultations and because there is no known biomarker and no cure. There is little acceptance, though awareness increases. General practitioners are the most competent in diagnosis and follow-up.

There are two age peaks of onset: 10-19 and 30-39 (Bakken 2014). There is a law to go to school in Norway. ME is a major cause for long school absences.

In 2016, following the paradigm shift that resulted from the publication of the IOM report in 2015, the Norwegian Research Council (*Forskningsrådet*) allocated 30 million NOK in earmarked funds for four ME research projects. Ongoing projects in Norway include:

- Genetics and autoimmunity by Lie and Viken + PhD Lande
- Defective Energy Metabolism by Hoel, Tronstad + PhD candidate
- Fecal microbiota transfer by Skjevling et al.
- Sociology by Anne Kielland et al. (FaFo, Sintef)
- 8 papers by Fluge/Mella eg. on Rituximab (negative result) and cyclophosphamide (whose effect is supported by an unblinded study).

A treatment centre with 12 beds for the severely ill was recently opened in Norway.

Denmark

In 2019, the Danish parliament *Folketinget* voted unanimously (170-0) for ME/CFS to be separated from functional disorders, and to treat it as a neurological disease following the WHO classification G93.3. The National Department of Health was called upon to update its information, but the National Board of Health has not carried the decision out, so in practice ME is still mainly treated as functional somatic disorder. People with a G93.3 diagnosis are often re-diagnosed as having common fatigue or with a functional somatic diagnosis specific for Denmark and offered cognitive behavioural therapy (CBT) and graded exercise therapy (GET), though there is little evidence of their efficiency and though GET is no longer recommended in updated guidelines.

Care and Research in Denmark (Dr. Jesper Mehlsen, Senior Consultant, Section for Surgical Pathophysiology and Klinik Mehlsen)

There is only one specialized ME clinic in Denmark, and it is private. It was founded in September 2018 and now has a staff of 10 employees and c. 650 clients with ME/POTS/LC. Distance consultations are usual because patients are unable to travel. It collaborates with labs in Aarhus for testing mitochondrial function and Berlin for anti-body testing. Canadian Criteria are used for diagnosis.
Mehlsen and colleagues are conducting drug placebo control trials for example on low dose doxycycline (where 65% improved) and changes in mitochondrial fatty acids.
There is a privately funded pilot project with a team of doctors going out to 20 severely ill ME patients all over Denmark to register and help them. A new scientific society on multiorgan disease has recently been founded. Danish general practitioners are becoming more aware that ME is not a functional disorder and that GET/CBT should not be recommended as curative treatments. Social security is slowly improving.

How to develop ME/CFS guidelines (Chief editor of guidelines, Dr. Jorma Komulainen, Finnish Medical Society Duodecim)

The recently published Finnish guidelines came about thanks to patient demand for equality. In 2018 the Finnish Medical Society Duodecim was allocated state funding from Parliament for preparing treatment recommendations. The funding was provided as a state grant through the National Institute for Health and Welfare (*Terveyden ja hyvinvoinnin laitos, THL*).

The medical society Duodecim has extensive experience in developing evidence-based treatment recommendations. Duodecim considered that there was not enough research literature on the subject to draw up evidence-based guidelines, so they opted for consensus recommendations instead. A panel of 19 people was invited to draw up the recommendations, supported by a writing team of 5 persons.

The recommendations were published in February 2021.[10] There is also a shorter version for patients and carers. Reactions have been positive. There is, however, no state funding for the implementation of guidelines, so it is up to each hospital how or whether to develop their treatment paths. Physicians have been taught about the new ME recommendations in medical congresses held in Oulu and Turku in 2021, which have been well attended with several hundreds of registered participants.

ME in the Young (Prof. emer. Ola D. Saugstad, University of Oslo)

There are few scholarly articles on the subject, but the review articles are excellent (Jason et al. 2012 and Speight 2020). It is known that there are two age peaks in incidence: 10-19 and 30-39 years (Bakken et al. 2014). International paediatric recommendations (Rowe 2017) and diagnostic criteria do exist (Jason et al. 2006), but there is a call for simpler case definitions.

ME manifests somewhat differently in children and adults (e.g., rash and abdominal pain more common in the young). Prognosis is better than in adults, but according to a 13-year follow-up study, many never recover fully (Bell 2001). Getting a diagnosis takes a long time and treatment is suboptimal.

Home schooling is often needed: according to a Norwegian patient survey, only 4% can go to school full time, 66% partially, and 29% are too ill for school all together. One out of four families with children with ME have been threatened by child protection. The newly published NICE guideline in the UK is promising as it includes a section on the safeguarding of families (NICE 2021 Chapter 1.7).

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[10] https://www.terveysportti.fi/apps/ltk/article/hsu00019

Prof. Saugstad's Take Home Messages

- Severe ME constitutes a major challenge for both patient and doctor
- Mismanagement in the form of "activation regimes" can result in permanent harm
- The patient deserves the total commitment of one doctor, who is willing to visit home on a regular basis
- Referral to a psychiatrist who does not believe in ME/CFS can be harmful
- The patient should be protected from sensory overload
- The doctor should resist the temptation to over investigate, or involve too many other professionals
- Nursing at home is usually far preferable to admission to a busy general hospital
- Tube feeding is indicated when the patient has problems with eating and drinking
- Urinary catherization may be helpful in reducing the stress of having to micturate
- Symptomatic treatment for pain and sleep problems is worthwhile
- Full recovery is possible
- The role of immunoglobulin deserves further study
- There is need to improve both undergraduate and postgraduate medical training in this area, and to provide greater resources for the patient population affected (cf. Speight 2020).

"It is […] concerning that the child welfare in several countries, including my own, starts custody cases, threatening to remove young ME patients from their families into emergency placement in youth centres or foster homes. These child protection cases are based on the not updated view that ME is a functional disorder that can be addressed by ignoring physical symptoms and increasing scholarly, physical, and social activity. Parents are accused of life-threatening neglect by letting their children rest in isolation. This attitude, however, ignores the international consensus definition of ME/CFS as a serious somatic disorder in which overexertion may have long-lasting or even permanent detrimental effects. To my knowledge, removing such patients from their parents has never been proven to be effective therapeutically.
To the contrary, such non-evidence based practice has been shown to contribute much harm and should not be accepted."

Prof. emer. Ola D. Saugstad,
"Myalgic Encephalomyelitis (ME) in the Young. Time to Repent"
Acta Paediatrica. 2020;109:645–646.

4 TOWARDS COMMON STRATEGIES AND STANDARDS

During the second part of the conference, participants were divided into breakout rooms for workshops on three topics: Research, Guidelines and Education. To optimize expert input and interaction, the setting allowed conference attendees to participate in more than one workshop.

4.1. Action Plan for Joint Research

Challenges

- *Lack of resources*: Research into ME is notoriously underfunded, so there is little incentive, especially for young researchers at the beginning of their career.
- *Lack of collaborative research efforts*: The Nordic research environment on ME is still rather fragmented, with few ongoing national and international initiatives.
- *Lack of reliable and routinely collected data:* Knowledge gaps due to underdiagnosis and misdiagnosis of G93.3. and/or poor use of registries.

Strengths

- The Nordic countries have similar medical systems with good patient registries.
- Nordic research cooperation would allow sharing data, infrastructure, and resources across national borders. The Norwegian ME biobank, for example, is a valuable resource that is already available for international research projects.
- Increased medical education and more uniform standards of diagnostics and better use of registries would benefit research: the more people that are correctly diagnosed with ME/CFS according to uniform case definitions the larger the cohorts that could then participate in research studies.
- Nordic patient associations are active and supportive of medical research.

Suggestions for the Development of Research Projects

- **Initiating Nordic Multi-Centre Randomized Control Trials (RCTs**) preferably based on previous RCTs **on promising pharmacological treatments** such as low dose naltrexone, low dose doxycycline, antibody removal, immunoglobulin, antivirals, cyclophosphamide, rintatolimod, immunisations, CBD-oil etc.
    - Studies should be sufficiently large high-quality RCTs with strict diagnostic criteria and include objective outcome measures (e.g., statistics on going back to work/study).

    - NordForsk programs can be proposed by national research funding organisations through the Open Invitation mechanism.
    - Any successful Nordic trial could be developed further via the European ME Research Group (EMERG).

- **Interdisciplinary studies** for example on T-cell exhaustion or the role of the glymphatic system in ME and Long COVID cohorts.
    - Such studies could fit under "Horizon Europe" for EU funding.
- **Genetic studies** for which there exists a good Nordic infrastructure.
- **Post-mortem studies** of tissue samples to examine persistence of viruses. Few such studies have yet been made (McGarry 1994; Richardsson 2001; Chia 2015) and all found enteroviruses in the brains of ME-patients.
- **Longitudinal studies** on paediatric cohorts with long school absences,
- **Epidemiological studies** to fill basic knowledge gaps about prevalence, incidence, life expectancy, mortality, etc.
- **Regular collaborative survey studies** in the vein of the ongoing "EMEA Pan-European ME patient survey".
- **Research into biomarkers and methods to measure disability**
- **Making a call for information and proposals** to map ongoing efforts, capabilities, and suggestions on how best to advance and accelerate medical ME research (cf. the US NINDS report 2019).
- **Involving patients** in scientific projects and study design (cf. WHO statement by Prof. Martin McKee)[11]
- **Developing an online ME research forum** for continuous updates on emerging evidence and treatment approaches (cf. the European ME Research Group) for sharing and expanding existing resources and expertise in the Nordic countries.
    - To reach the target group of primary care physicians any resource needs active "marketing", not just a website.
- **Developing a Nordic ME knowledge centre/advisory group** of internationally renowned experts and experienced national practitioners that could be consulted by medical professionals from places with limited services for ME/CFS (cf. the European ME Clinicians Council)

For more detail on European initiatives, see chapter 5.

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[11] https://www.euro.who.int/en/media-centre/events/events/2021/02/virtual-press-briefing-on-covid-19-understanding-long-covid-post-covid-conditions/understanding-and-managing-long-covid-requires-a-patient-led-approach

4.2. Guidelines and How to Develop and Implement Them

Current situation

It is the responsibility of medical scientific institutions to compile, update and disseminate the state-of-the-art in the diagnosis and treatment of diseases. This is achieved through the consensual preparation of high-quality, evidence-based clinical guidelines.

- Norway was the first country in the Nordic region to develop national ME/CFS guidelines with its "Nasjonal Veileder" in 2015.[12]
- Sweden has so far decided against developing national guidelines based on a systematic literary review and report concluding that the evidence-base is still insufficient (SBU 2018; Socialstyrelsen 2018).[13] There are, however, recommendations such as Nationellt kliniskt kunskapsstöd,[14] Vårdguiden,[15] and www.viss.nu for Stockholm County.[16]
- In 2021, the Finnish Medical Society Duodecim published national consensus recommendations.[17]
- So far, Denmark and Iceland do not have official ME guidelines, however, the ME association of Iceland has recently produced a translation of the Mayo guidelines (2021) and made it available on their website.[18]

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[12] https://www.helsedirektoratet.no/veiledere/pasienter-med-cfsme-utredning-diagnostikk-behandling-rehabilitering-pleie-og-omsorg/CFS-ME%20–%20Nasjonal%20veileder%20for%20utredning,%20diagnostikk,%20behandling,%20pleie%20og%20omsorg.pdf/_/attachment/inline/63b695db-59b0-48e9-9da5-f49a4de282ba:35fd11d1509dd099b5bf142021e5813d10070553/CFS-ME%20–%20Nasjonal%20veileder%20for%20utredning,%20diagnostikk,%20behandling,%20pleie%20og%20omsorg.pdf

[13] https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2018-12-48.pdf

[14] https://nationelltkliniskt kunskapsstod.se/dokument/176d1b90-4fb6-4731-a544-1320d63fd741

[15] https://www.1177.se/sjukdomar--besvar/hjarna-och-nerver/langvarig-trotthet-och-narkolepsi/mecfs/

[16] https://viss.nu/kunskapsstod/vardprogram/me-cfs

[17] https://www.terveysportti.fi/apps/ltk/article/hsu00019

[18] https://www.mefelag.is/bateman-greiningin-2021

Opportunities

The European ME Network (EUROMENE), a COST action project active in 2016-2020, has produced several useful reports and publications that are available on their website.[19] Notably, in 2020, the 55 experts of EUROMENE published consensus recommendations on the diagnosis, service provision, and care of people with ME/CFS in Europe.[20] Similarly, in April 2021, the US ME/CFS Clinician Coalition published recommendations for medical providers[21] followed by the Mayo Clinic consensus recommendations (Bateman et al. 2021).[22] In October 2021 the evidence-based NICE guideline in the UK replaced previous ME guidelines from 2007.[23] All these documents are mutually coherent and provide a solid foundation for the development of uniform standards. There is no need to reinvent the wheel.

Challenges

International guidelines are not binding for the clinical care of individual Nordic countries, so in practise, diagnosis and treatment of ME patients varies greatly depending on in which Nordic country or even region, a patient happens to live. This is a far cry from equality.

Even in Nordic countries and regions where national recommendations *do* exist, they are not always fully implemented in practice, because of lack of knowledge and training, resources, and specialized health care units to refer ME patients to.

Sometimes there may even be resistance against implementation, as was the case in the UK with the recently published NICE guideline. The publication was notoriously delayed due to demands by professional interest groups that were reluctant to accept some of the evidence-based recommendations.

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[19] http://www.euromene.eu/workinggroups/pubblications/pubblication.html

[20] http://euromene.eu/meetings/EUROMENE_recommendations_Booklet.pdf

[21] https://drive.google.com/file/d/1N51cJ_HQ0jtjQLTeivWBUT7krySJbNrx/view

[22] https://www.mayoclinicproceedings.org/article/S0025-6196(21)00513-9/fulltext

[23] https://www.nice.org.uk/guidance/ng206

Suggestions for Developing and Implementing Guidelines

The Nordic countries would have much to gain from adopting to uniform policies and standards. But what can be done to achieve greater consensus and equitable treatment in the Nordic countries? This, among other questions, was discussed in the second breakout room. Below are the main points that emerged:

- Grassroots are key for prompting the development of guidelines
- Guidelines are necessary
- Where there are no national guidelines, existing foreign guidelines could be adopted (if there is a will, there is a way)
- Implementation needs to be carried out by the professional organizations responsible for taking care of the patients
- The nearer to the medical organizations the guidelines are developed, the less resistance there should be in implementing them
- Guidelines are just a start: expertise develops through practical experience of taking care of ME/CFS patients
- Young professionals are key, established ones may be harder to retrain
- Opinion leaders have been important in other diseases, but it may be harder to show direction in ME/CFS.

4.3. Medical ME/CFS Education and How to Improve It

The State of Medical ME/CFS Training

It is one of the duties of practitioners to keep abreast of developments and new findings in their respective fields. There is, however, little or no updated medical training on ME available, so the condition is not yet well recognized. A recent study confirms that there has been “an international paradigm shift in the literature, which defines ME/CFS as a multisystem disease, replacing the psychogenic narrative, yet little has changed in medical education and most cases of ME/CFS go undiagnosed” (Muirhead et al. 2021). The limited understanding of ME as an independent biological condition is documented in recent studies:

- 39% of the clinicians in the UK do not recognize PEM as a main diagnostic criterion (Hng et al. 2021).
- 72% of the general practitioners in Europe do not accept ME/CFS as a genuine clinical entity and, even when they do, they lack confidence in diagnosing or managing it.
- Skepticism and negative attitudes are common
- Most ME cases remain undiagnosed (Cullinan et al. 2021).

Lack of knowledge leads to missed and delayed diagnoses and treatments, prevents individuals with ME/CFS from receiving sickness and disability allowance, and increases disease burden and costs. So, education is key. To quote a 2020 EUROMENE report, it is "extremely important to prioritize research and education of health professionals and others in society, to address the scientific and societal poor understanding of the problem faced". The ongoing COVID-19 pandemic adds to the urgency for developing educational material and specialization in the field of postviral conditions.

Current Medical ME/CFS Training in the Nordic Countries

Medical school training on ME/CFS is limited to a couple of hours or a few pages of material at best. There are no postgraduate specializations for postviral conditions in the entire Nordic region. Many of the few Nordic ME experts are retired or retiring.

Finland: Medical education is offered by five universities: Helsinki, Tampere, Turku, Oulu and Eastern Finland (Kuopio). The basic medical education lasts for a minimum of six years and leads to the degree of Licentiate of Medicine. No systematic education on ME/CFS is provided. In 2019-21 any courses related to ME/CFS at the Helsinki university dealt with vaguely defined concepts of "chronic fatigue syndrome", and the condition was presented as if it were a functional disorder. Continuous professional training on ME is equally sparce and comes from representatives of different schools (biopsychosocial vs. biomedical), which is confusing. Doctors are to use the recently published Finnish Good Medical Practice recommendations. The Finnish medical society Duodecim arranges five annual medical congresses for doctors and some of them have included material on ME/CFS. Associations for nurses and physiotherapists have also organized online ME training based on the new national recommendations. Other, more informal meetings for professionals, still tend to present "CFS" as a functional disorder.

In recent years, involvement of experts by experience in serious information and training events has become standard. There used to be only 3-4 trained experience experts for ME in Finland, but thanks to a SLME pilot project, where a tailor-made training was developed, 19 new experts by experience graduated in June 2021 and can be consulted by distance or in person in most parts of the country (**Figure 4**).

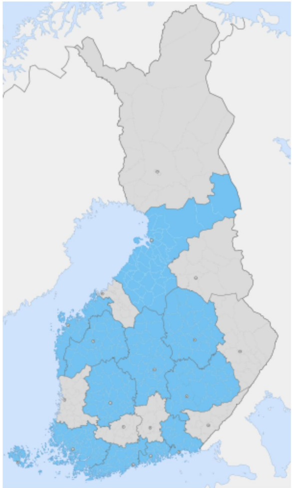


Figure 4. Geographical distribution of experts by experience in Finland © Samuli Tani.

Sweden: It is up to the faculties to decide the curricula of basic medical education, and education is often limited to a few pages in textbooks. The lack of ME knowledge among Swedish general practitioners is documented (SBU report 2018).

The Swedish ME association (RME) is a major source of good information for medical professionals and medical students are invited to their annual conference, but they are allegedly reluctant to join events arranged by patient organizations.

The Swedish Medical Journal (*Läkartidningen*) has published useful articles on ME and organizes 4-5 half-day conferences per year, which have been well-attended by professionals. The Swedish Medical Association (*Läkarförbundet*) also arranges popular seminars.

Norway: The situation resembles that of Sweden. There is a lack of medical school education on ME, maybe 2-3 hours during the entire medical studies. There are national ME guidelines since 2015, recommending the use of Canadian Consensus Criteria, but guidelines would need to be better implemented and updated. No medical specialization regards ME as their responsibility.

Denmark: The situation resembles that of Norway and Sweden. Medical school education on ME narrows down to 2-3 hours and students are mainly told ME is a functional somatic disease. In recent years, however, neurologists and general practitioners have shown interest in the topic by inviting ME specialists from clinic Mehlsen to lecture on ME. It is difficult to get the ME diagnosis as no speciality seems to take responsibility for the patients.

Iceland: ME/CFS has been known in Iceland since the Akureyri outbreak in the winter of 1948–1949 in a boarding school with almost 500 cases. Medical school training on ME used to be very good and the disease was rather well recognized. The situation does not seem to be quite as good anymore and it is harder to get a diagnosis than before.

Current Nordic Educational Initiatives

Patient associations have long been among the best sources for updated information on ME/CFS. They provide translations of useful resources and make them accessible on their webpages for medical providers and for patients to print them out for their doctors.

Nordic professionals have free access to the educational material provided by global organizations. For links to existing online resources see Appendix F.

A Toolbox for schools has been developed in Norway and is being adopted in Denmark and Sweden. The ME associations of Finland and Iceland would need more funding to be able to participate in this joint Nordic project.

Suggestions for How to Improve Education on ME (and post-viral conditions):

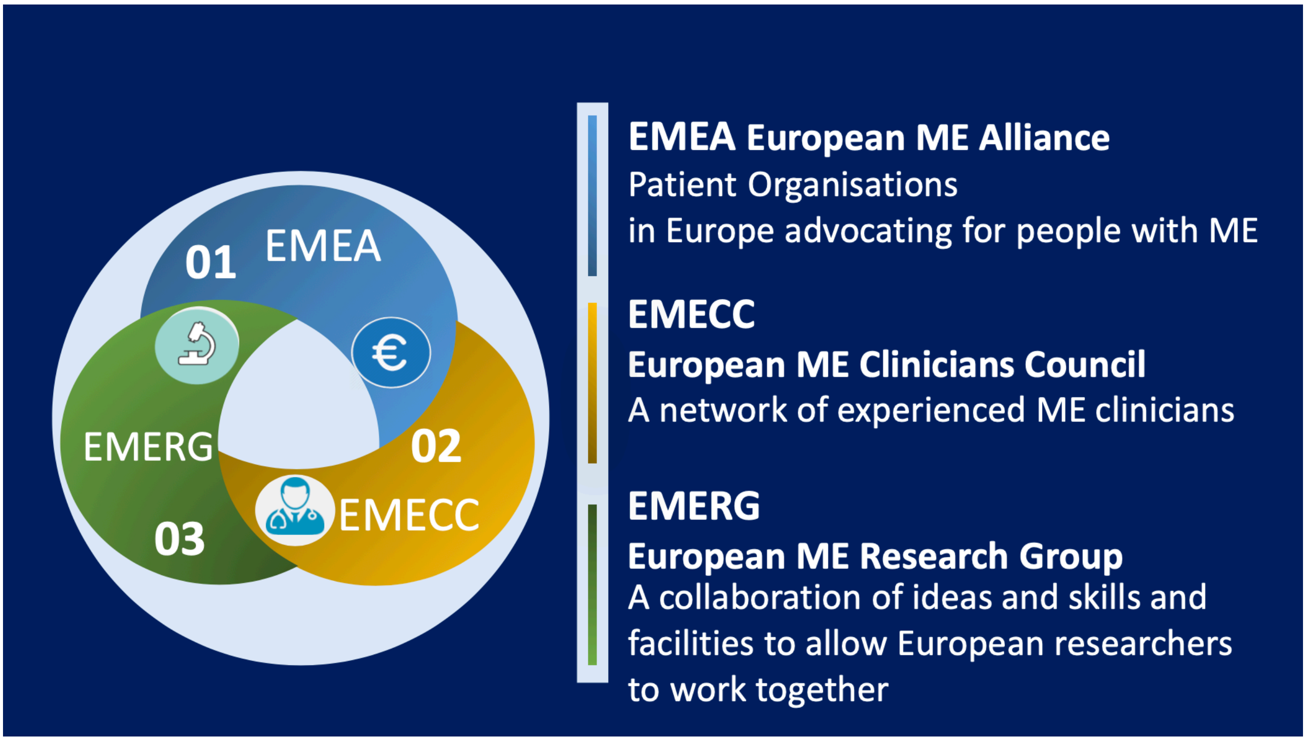
- Introducing **undergraduate training** on ME/CFS in medical school curricula.
- Establishing a postgraduate **specialization**
- Establishing a **Nordic doctoral ME fellowship**
    - PhD candidates are already involved in medical ME research projects in Norway, Denmark, and Sweden. The first post doc student in Sweden was recruited on 15 October 2019.
- Developing an **Electronic Doctor's Handbook or "Toolbox"**
    - As noted, a Nordic information package on ME for schools has already been developed (the Norwegian "Toolbox" with its booklet, animations, and lecture soon to be available in 3-4 Nordic languages).
    - World Physios Day has exemplary resources on Long COVID with a website, 19-page briefing paper in 9 languages, online printable factsheets in 50 languages, online courses, and modules.
    - In Norway, there is an electronic doctor's handbook for ME. The material could be translated into other Nordic languages by patient associations and proof-read by medical associations.
- **Developing a Nordic online course for Continuing Professional Development** that provides university-level education for medical providers, students, and researchers.
    - The educational material should be based on evidence and consensus documents, such as guidelines and be accredited by internationally renowned ME experts, such as representatives from the European ME Clinician's Council. Some educational resources are already available on their webpages: http://www.emecc.org/education.shtml.
    - An e-learning platform could consist of shared Nordic resources such as webinars, lectures, videos, case studies, handouts as well as interactive elements such as Q&A, workshops, and discussions
    - For examples of existing educational online resources on ME in other countries, see Appendix F.
- **Establishing trainee programs** for medical students in ME clinics and wards, so that they could interact with actual ME patients during the clinical period of their courses.
    - Clinical practice with instant feedback is the most efficient way of learning.

- **Arranging study visits in ME clinics** for established medical professionals.
- **Organizing regular Nordic symposiums** or lecture tours
    - Physical, digital or hybrid events
- **Involving trained experts by experience** in training events for professionals,
    - This is already often the case in quality events in Norway and Finland.
    - One should distinguish between officially trained experience experts and self-proclaimed experts, claiming to have recovered with potentially harmful commercial training programs with no evidence-base.
    - Experts should set a positive example of symptom management.

> *"Given what we have learned in the past eight years*
> *about this illness,*
> *it is intellectually embarrassing*
> *to suggest that ME is a psychological illness."*
>
> – Prof. Betsy Keller, PhD
> Ithaca, NY (Department of Exercise and Sport Sciences) in 2015.
> Scientific Advisor to the Medical ME/CFS Association of Finland

5 ME/CFS INITIATIVES IN EUROPE

This report has focused on the Nordic situation, but the endeavour is part of a wider European strategy, which is also why The European ME Alliance played a key role in the Nordic conference. A successful Nordic model could serve as a template and be adopted on the European level, paving the way forward.



EMEA European ME Alliance
Patient Organisations
in Europe advocating for people with ME

EMECC
European ME Clinicians Council
A network of experienced ME clinicians

EMERG
European ME Research Group
A collaboration of ideas and skills and facilities to allow European researchers to work together

Figure 5 The Synergy between European Strategies.

The synergy behind current European strategies

European ME Alliance (EMEA) [24]

Chairman Richard Simpson

One central player aiming to align research and funding activities on a European and international level is the European ME Alliance. Founded in 2008, EMEA is a European umbrella organization now bringing together 17 national patient advocacy groups from the following countries:

- Belgium
- Croatia
- Denmark
- Finland (2)
- France
- Germany
- Netherlands (4)
- Iceland
- Ireland
- Italy
- Norway
- Serbia
- Slovenia
- Spain
- Sweden
- Switzerland
- The United Kingdom (2)

EMEA “gives a voice for people with ME in Europe and is the European partner for facilitating high-quality biomedical research into ME or ME/CFS.” For the last 15 years, it has arranged the annual “Invest in ME Research: International ME Colloquiums and Conferences in London”. [25]

Together with the Norwegian ME Association, EMEA has recently performed the pan-European survey (forthcoming 2022) with more than 11,000 participants from several European countries. It is thus probably the largest ME patient survey of all time.

EMEA is in the board of The European Federation of Neurological Associations (EFNA).

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[24] https://www.europeanmealliance.org/index.shtml

[25] https://www.investinme.org/cindex.shtml

European ME Clinicians Council (EMECC) [26]

The European ME Clinicians Council (EMECC) is a network of experienced ME clinicians from the EU member states. The aims of EMECC are to bring together clinicians in the field of ME to review the current state of knowledge, to present and discuss the latest initiatives, and to foster collaboration. EMECC is also a means to support and influence the research strategies created by the European ME Research Group (EMERG).

European ME Research Group (EMERG) [27]

A collaboration of ideas and skills and facilities to allow European researchers to work together. Major European countries are working together in EMERG to establish a strategy of high-quality, coordinated biomedical research into ME. EMERG cooperates with the clinicians in EMECC and with European ME patient groups and charities within the EMEA to provide a powerful combination of high-quality research, clinical expertise, and patient participation.

> *"There is so little funding and comparatively so few resources available that research should not be done in isolation. With EMERG there is opportunity to pull it all together in Europe.*
> *That is the way forward."*
>
> – Richard Simpson

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[26] http://www.emecc.org/index.shtml

[27] https://www.emerg.eu/em-team.shtml

6 CONCLUDING REMARKS AND NEXT STEPS

The present report provides an inventory of the strengths and potentials of Nordic healthcare and research in the field of ME/CFS, as well as exposing inadequacies and discrepancies.

- National ME guidelines may be missing, dated, or not fully implemented
- Insufficient number of specialised ME clinics/units and lack of expertise
- Biomedical ME research is extremely underfunded
- Lack of updated medical education for health care professionals
- Some treatments/measures are misdirected or even harmful
- Patient rights are infringed upon if adequate treatment and social security are denied or vary depending on in which region or country the patient happens to live.

The report documents an urgent need for developing and implementing uniform standards in the Nordic countries to be able to ensure the best and most equitable medical and social care. The unification of diagnostic and therapeutic measures would benefit everyone and reduce both individual and societal burden. To achieve this, collaborative ME research and educational projects and policies are needed. Joint strategies and standards suggested include:

- **Research:** Funding and setting up robust medical research projects, preferably multicentre RCTs on promising treatments and interdisciplinary studies involving long COVID cohorts. A request for information and proposals could assist in the choice of project. Developing an online medical research forum. Arranging symposiums.
- **Education**: Developing informational and educational materials for
  - graduate and postgraduate medical students including in-service training
  - primary care physicians (electronic handbook and/or modules for continuing professional development)
  - schools, educational staff, and child welfare (cf. ongoing Toolbox project)
  - the public in general.
- **Guidelines:** Adopting uniform nomenclature, case definitions, treatment recommendations, and methods for data collection in compliance with the WHO and evidence-based recommendations.
- **Public Health Policy**: Increased public funding for ME/CFS research and for improved and equitable access to care, services, and disability benefits. Setting up a Nordic centre of excellence.

The report will hopefully serve as a catalyst to accelerate rapid, decisive and forward-thinking policies and projects. Millions of patients in Europe have been waiting for years for recognition and support. This report will hopefully prompt action that will ultimately improve the situation of ME sufferers and their families not only in the Nordic countries but everywhere in the world.

"We haven't had anything to offer to this group,
and they have been met with negligence in the health care system.
This is because there have been a lot of prejudices towards this illness;
that this is the result of a psychologically, almost wanted illness. It really is a scandal.
The patients have been met with a lack of respect just because
we haven't had enough knowledge.
The worst thing is that we haven't worked very hard to get this knowledge either.
It is important that the health care system make research on ME a priority"

PM Erna Solberg
in an interview to the Norwegian national television in NRK in 2015
(as quoted in ME-Pedia)

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WHO Coronavirus (COVID-19) Dashboard with Confirmed Cases. Available online: https://covid19.who.int/.

Appendix A. Letter of Intent

THE NORDIC ME-NETWORK
Suomen lääketieteellinen ME/CFS-yhdistys ry
00320 Helsinki
Matkamiehenpolku 2 A 4
admin@slme.fi
20/09/2019

LETTER OF INTENT

We submit this letter with the intent to partner and/or collaborate with the following patients' organisations.

- ○ Riksföreningen för ME-Patienter (RME)
- ○ Norges Myalgisk Encefalopatiförening
- ○ ME Foreningen i Danmark
- ○ Suomen ME/CFS-Yhdistys ry.
- ○ Suomen lääketieteellinen ME/CFS-yhdistys ry

The interest seeks to advance public knowledge on Myalgic Encephalomyelitis / Chronic Fatigue Syndrome abbreviated as ME/CFS and to change the course of what is known of the disease.

We intend to organise annual conference meetings at Nordic airports, starting at the Helsinki Airport in Finland, to engage these patient associations, various ministries of social affairs and health, health care providers, parliamentarians and insurance industry in advancing public health care, and awareness surrounding the effects of the disease.

The proposed network should be achieved through short-, medium-, and long term plans. Short term plans would involve identifying the partners and associates such as yourselves. Medium-term plans would be to apply for funding both state and private based, gather attendees and organize the first meeting. Long-term plans would involve creating an annual common Nordic ME survey whose results will be published at our annual conference meetings, and signing cooperation agreements with various partners and associates.

Proposed partner organisations should remain responsible for their members costs and expenses, and additional costs associated with this project.

Signed digitally on individual pages by the named organizations.

Appendix B. Conference Participants and Affiliations

*Lead author **Co-author

*PhD Katja Brandt	Medical Association of ME/CFS in Finland, secretary
** Samuli Tani	Medical Association of ME/CFS in Finland, chair
Richard Simpson	European ME Alliance, Chair
Dr Chief Jorma Komulainen	Finnish Medical Society Duodecim, Chief editor of guidelines
Prof. Markku Partinen	University of Helsinki, Finland
Dr Olli Polo, MD	Suomen ME/CFS yhdistys, Finland, board member
PhD Kerstin Heiling leg.	psychologist Riksförbundet för ME-patienter, Sweden
Ass. Prof. Sture Eriksson	Umeå University, Sweden
Dr Per Julin, MD, PhD	Karolinska Institute, Specialist in Rehabilitation Medicine, Stockholm, Sweden (excused 8.11.2021)
Rune Hoddevik	Norges Myalgisk Encefalopati Forening, Norway
Prof. Kristian Sommerfelt	University of Bergen, Norway
Prof. Emer. Ola D. Saugstad	University of Oslo, Norway
Cathrine Engsig	Chair of ME Foreningen, Denmark
Prof. Jesper Mehlsen	Klinik Mehlsen, Denmark
Guðrún Sæmundsdóttir	Chair of ME félag Íslands, Iceland

Appendix C. Conference Agenda

NOON SESSION:

Time	Subject	Presenter
12:00	**NOON SESSION: ME/CFS - STATUS UPDATE ON HEALTH CARE AND RESEARCH IN THE NORDIC COUNTRIES**	
12.00	Introduction: European ME Alliance	Richard Simpson, Chair, European ME Alliance
12.05	Patient organisations-Brief introductions	Finland, Denmark, Norway, Iceland, Sweden
12.30	STATUS UPDATE – Sweden	PhD Kerstin Heiling leg. psychologist and Ass. Prof. Sture Eriksson
12.45	STATUS UPDATE – Norway	Prof. Kristian Sommerfelt
13.00	STATUS UPDATE –Denmark	Dr. Jesper Mehlsen
13.15	STATUS UPDATE –Finland	Prof. Markku Partinen
13.30	**BREAK**	

AFTERNOON SESSION:

Time	Subject	Presenter
	AFTERNOON SESSION: TOWARDS COMMON STRATEGIES AND STANDARDS	
14.00	Creating ME/CFS recommendations	Ass. Prof. Jorma Komulainen,
14.20	ME guidelines	Dr. Per Julin
14.40	ME in the Young	Prof. emer. Ola D. Saugstad
15.00	Break-out rooms (3x4 persons) Topics: *1) Action plan for a common Nordic/European ME/CFS research project 2) How to successfully develop/implement an ME/CFS guideline?* *3) Ideas on a common Nordic/European teaching tool for ME/CFS*	
15.30	Discussion:	Strengths of Nordic health care and research resources and how to put them into good use
16.30	Conclusion	

Appendix D. Survey to the member associations of the Nordic ME Network for the Helsinki Airport Meeting 25.3.2020

ME/CFS: Health Care and Research in the Nordic Countries 2020

Please complete and return by 6 March 2020 to admin@slme.fi.

1. Name of your **patient organization**:
   - Year when founded
   - Number of members
   - Link to homepage, if possible

2. What is the **name** most commonly used about ME/CFS in your country?
   - ME as in myalgic encephalomyelitis
   - ME as in myalgic encephalopathy
   - ME/CFS
   - CFS/ME
   - CFS
   - SEID
   - Something else (what):

3. Estimated **number of ME/CFS patients** in your country:
   - Total
   - Diagnosed cases
   - New cases diagnosed last year

4. Does your country have a) a **national registry** for ME/CFS cases?
   - Yes
   - No

   b) a **biobank** for ME/CFS?
   - Yes
   - No

   c) **national guidelines** for diagnosis and treatment of ME/CFS?
   - Yes
   - No

5. What are the “most official” **medical guidelines/recommendations** for ME/CFS in your country (name of document plus link or source information)
   - for adults?
   - for paediatric patients?

6. Which **diagnostic codes** are most commonly applied for ME/CFS by healthcare professionals in your country?

- G93.3
- F48
- R53
- A combination of these
- Something else (please specify):

7. Which **case definitions** are recommended/most commonly used in clinical practice?

- Oxford
- Fukuda
- CCC
- ICC
- IOM 2015
- A mix of these
- Something else (please specify):

8. Respecting WHO classifications: Is ME/CFS categorized as a Functional Disorder / MUS (medically unexplained symptom) by the health care authorities in your country?

- Yes
- No

9. Access to care: Number of **specialized ME/CFS clinics** in your country

- Public:
- Private:

10. What are the methods accepted in the **treatment/management** of ME/CFS in your national public health care system?

- Medical treatments:
  - B12-injections
  - Low-dose naltrexone (LDN)
  - Immunological treatments
  - Fecal Microbiota Transplant
  - Others (which?):
- Symptom relief
  - Pain killers
  - Medication for sleep problems
  - Antidepressants
  - Nutritional supplements
  - Intravenous saline solution
  - Others (which?):
- Therapies and self-managing strategies

- Cognitive Behavioural Therapy
- Graded Exercise Therapy
- Lightning Process
- Dynamic Neural Retraining System
- Other commercial/alternative therapy (which?)
- Pacing
- Mindfulness
- Sick leave
- Others (which?):

11. **Research initiatives**: What, if any, notable research projects dedicated to ME/CFS are there currently in your country?

12. **Social security and disability allowance**: Is ME/CFS fully acknowledged by your national insurance institutions? What, for example, are the chances (%) that medically documented disability caused by ME/CFS is accepted as a valid motif for state sickness and disability allowance?

13. Notable **political developments**:
    - Our Prime Minister publicly apologized for the wrongful treatment of ME patients
    - Our Parliament has unanimously voted for implementing WHO diagnostic codes rather than labelling ME as a Functional Disorder
    - An official all-party ME group has been created in our parliament
    - Something else (what?):

14. Please name some of the biggest **challenges** in your country in ensuring ME/CFS patients' equitable access to treatment, services and support?

15. Please name any notable **advances or success stories** that your country can be proud of and could serve as constructive examples for other nations?

16. **Additional comments** (please feel free to add ideas, links to useful material or suggested topics for further discussion)

Appendix E. Survey Results

1	Question	Norway	Sweden	Finland	Denmark	Comment
2	Name of disease	ME as in myalgic encephalopathy	ME or ME/CFS	Chronic fatigue syndrome (ME/CFS)	ME - Kronisk træthed	Nomenclature varies
3a	Nr of patients	c. 15,000-40,000	41,200 (based on 0,4% of 10,3 million)	>10,000 (based on 0,2%)	10,000-20,000	Lack of precise data
3b	Nr of patients diagnosed	15,000 [sic]	Not known	c. 700 (if private diagnoses count)	746 during the years 1994-2013 (hospitals numbers only)	Extremely underdiagnosed in most countries
3c	Nr of patients diagnosed in 2020	c. 400	Not known	Not known, very few	Not known	Lack of data due to poor use of diagnostic codes and registries
4a	Patient registry for ME patients	Yes	No	Yes, but little used	No	Lack / poor use of registries
4b	Biobank for ME patients	Yes	Yes	Yes	No	Good possibilities for genetic studies
5a	National guidelines for adult ME patients	Yes ("Nasjonal Veileder" 2015)	No	Yes (Good Medical Practice consensus recommendations 2/2021)	No	Only Finland and Norway have national recommendations
5b	National guidelines for children	Yes, same as for adults	No	Same as for adults	No	Ibid.
6	Diagnostic code/s used	G93.3	G93.3	G93.3 should be used, but is underused	G93.3, F48, R68.8, A9B1	Denmark does not adhere to WHO classifications
7	Diagnostic criteria used	ICC [sic]	CCC, but with varying interpretation.	CCC, ICC and IOM (should include PEM)	Oxford, Fukuda, NICE 2007	Lack of uniform case definitions. Denmark uses dated definitions ignoring the hallmark symptom of ME (PEM)
8	Is ME treated as Functional Disorder?	No	No	Yes	Yes	Lack of adherence to inter- and intranational recommendations and classifications in Denmark and Finland
9a	Number of specialised clinics, public	Clinics at all regional university hospitals	One specialized ME/CFS clinic with official care contract.	None, only a Functional Disorders clinic at Helsinki University Hospital and a pilot project for “tired patients” in Tampere University Hospital	None	Access to specialised ME clinics and wards is limited, especially in Finland.
9b	Number of specialised clinics, private	Several but no overview of how many	Two pain clinics accept ME/CFS-patients, mixed experience by patients	None, unless we count a Helsinki sleep clinic	One for 4.4M inhabitants 16+ of age	Lack of access to care and choice
10	Main treatment methods offered	Pacing, CBT/GET, Lightning Process	Pain killers, medication for sleep problems, antidepressants, pacing, sick leave. B12 injections and LDN are prescribed by special clinics, but not supported by all GPs	Net therapy for functional disorders, sometimes LDN	Psychiatric counselling or hospitalization, antidepressants, CBT/GET, mindfulness, sick leave	Notable differences in treatment methods between the countries, inequity
11	Approximate % of applications for social security granted	[not stated]	Maybe 50%	Maybe 34%. In 2019, one third of the working-age ME patients receive benefits (20% pension + 14% sickness leave). In 2012, 131 persons with G93.3. diagnosis in Finland received sickness benefits and 482 pension or rehabilitation support (Vanhanen 2012). Rehabilitation support is allegedly never granted (Ahonen & Aranko 2019)	May take 8-10 years without legal help	This is discriminatory and goes against Nordic values of equality and transparency. The rule of law should be reinforced.

12 a	Ongoing biomedical research projects	1. Genetic studies to investigate the potential involvement of the immune system and reveal biomarkers, Oslo University Hospital 2. HLA genes, Oslo University Hospital 3. Defective energy metabolism in ME/CFS, University Hospital in Bergen 4. Fecal Transplant Research Project, University Hospital in Northern Norway (UNN) University Hospital in Northern Norway (UNN) 5. Health-related quality of life in adolescents with CFS/ME, a cross-sectional population based Norwegian study, St. Olavs Hospital, Trondheim	1. Uppsala university: Jonas Bergqvist et al., OMF-supported centre with focus on advanced analysis in clinical chemistry 2. Linköping: Anders Rosén's group with focus on immune system studies 3. Stockholm Bragée Clinic with focus on clinical data, clinical chemistry, and cervical instability 4. Stockholm Karolinska Institute based group with focus on clinical symptoms and clinical chemistry analysis 5. Umeå: Senior researcher engaged, but still in planning phase. Systematic biobanking initiated.	1. Tampere University Hospital: Salonen et al	1. PhD students Anne Sophie Schou and Ana Gonzales: Mitochondrial function in ME 2. Klinik Mehlsen: Genetic survey in collaboration with Oslo University and projects with ME clinic in Stockholm and Universities in Aarhus, Uppsala and North Carolina, USA.	Norway and Sweden have a good start, while Denmark and Finland lag behind
12 b	Ongoing other research projects	Tjensten og MEg – Et forskningsprosjekt, Fafo & SINTEF.	Patients with ME/CFS and Sickness behaviour at Karolinska Institutet, Martin Jonsjö Quality Register for ME/CFS, Sture Eriksson et al	Hiekkala et al. Invalidiliitto.		More coordinated research and research funding are needed
14	Main policy advances	St. Olav's Hospital, Trondheim	Parliamentary hearing 6/2021	All-Party Parliamentary group founded in 2019, at least 5 queries	Parliament voted for respecting WHO codes for ME classification	Fair/good political involvement
15	Main challenges	The psychosomatic school is powerful and does not recognize biomedical research. They have had a big influence on the medical profession and Nav (Norwegian Labour and Welfare Administration). The Lighting Process, an alternative treatment which claims to cure ME patients with a 3-days course, costing NOK 17 000, has had a huge impact on the medical profession and Nav. Some people say they have 'recovered' but have not returned to school/work. Many have had severe relapses. Some GPs and Nav offices demand that patients try this "treatment".	A report from the National Board of Health and Welfare published in Dec 2019 concluding that no official guidelines could be issued since there is no agreement in the medical profession about ME/CFS. Now healthcare decision makers all over the country refer to this report as an excuse for not doing anything.	1. ME (or "CFS" as it is often called) is treated as a Functional Disorder and confounded with other disorders 2. Lack of updated medical training. 3. Public health care promotes commercial net therapies that are not backed up by evidence. 4. No truly specialized ME care, and little chance of sickness allowance. 5. Children with ME have been wrongfully taken into forced custody 6. No funding for biomedical or sociological ME research, only functional disorders studies supported. 7. Health care policy is based on the opinions of a small group of doctors with risk of conflicting interests.	Knowledge about bio-medical research is lacking in medical training, psychiatry lobbyism, economic cut-downs, health insurance not recognizing ME as a physical illness.	Limited access to medical care and insurance coverage, unproportionate investments into biopsychosocial hypothesis compared to biomedical research.
15	Main advances	ME was officially recognized in 1995. That made a huge difference to the patients as they could claim benefits and other services.	The Swedish Agency for Health Technology Assessment and Assessment of Social Services (SBU) published a knowledge review in Dec 2019 stating that research based on the Canadian Criteria does not give support to any treatment for ME/CFS, but that patients deserve care and recognition. Specialized clinics are recommended. Media attention often initiated by patients has increased public awareness about ME/CFS	19 new experts by experience on ME graduated 6/2021	The Danish Parliament unanimously voted for implementing WHO diagnostic codes rather than labelling ME as a Functional Disorder. A growing ME-community where patients more willingly are present in media thus making ME visible and in the public debate. Yearly demonstration in Copenhagen on the international ME-day 12th of May. Showing the film "UNREST" more than 10 times in public events	Good, often patient-led, initiatives for increased awareness

Appendix F. Examples of Educational ME/CFS Resources

EU

- European ME Clinicians Council (EMECC) http://www.emecc.org/education.shtml

USA

- Centres for Disease Control https://www.cdc.gov/me-cfs/healthcare-providers/medical-students.html
- Video Unrest Film + Diagnosis and Management of Myalgic Encephalomyelitis and Chronic Fatigue Syndrome (11 minutes)
- US Clinicians Coalition (Bateman et al. several modules for free) https://mecfscliniciancoalition.org/medical-education/
- Workwell Foundation https://workwellfoundation.org/educational-videos/

- https://www.meaction.net/cme-courses/ (excellent summary of resources)

UK

- https://www.studyprn.com/p/chronic-fatigue-syndrome (Nina Muirhead) incl. 10 clinical cases

- https://www.studyprn.com/p/chronic-fatigue-syndrome (Charles Shepherd)

- The IiMER conferences have all been cpd-accredited and the videos from all conference presentations since 2006 are available to the public on this page – https://www.investinme.org/iimec-conferences.shtml

Australia

- https://www.thinkgp.com.au/education/mecfs

World Physiotherapy Toolkit on Long COVID:

- https://world.physio/toolkit/world-pt-day-2021-information-sheets-english