



European ME Alliance, Sønder Alle 5, st 3, 9500 Hobro, Denmark
Email: info@euro-me.org web: www.euro-me.org

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FOR IMMEDIATE RELEASE:



Press Release from the Norwegian Directorate of Health

Oslo, June 23, 2011

Today the Norwegian Directorate of Health has published their views of reports from The Foundation for Scientific and Industrial Research at the Norwegian Institute of Technology (SINTEF Technology and Society) and Norwegian Knowledge Centre for the Health Services regarding the current scientific evidence based knowledge status on ME/CFS, evaluation of research findings to date, and their recommendations to the Ministry of Health and Care Services, which has the overall responsibility for government policy on health and care services in Norway.

Many patients are in need of services based on collaboration between primary and tertiary health care services. Unfortunately this collaboration does not work well enough today.

The Directorate of Health has responded to the commission from the Ministry of Health and Care Services, with the following answers regarding main conclusions and recommendations.

The complete answer from the Directorate of Health can be found in the attachments listed on the right side of the website [documents in Norwegian only – see the links to website below].

Main conclusions based on reports from the Norwegian Knowledge Centre for the Health Services

- Today an evidence based knowledge base does not exist to justify publishing national instructions or a guide.
- The Directorate of Health, based on available reports, acknowledges that it will still take time to build good, robust patient service courses for this group of patients.
- The review of current scientific knowledge does not support an earlier recommendation to use the NICE Guideline.
- The review does not, on a general basis, support recommendations for individualized exercise therapy (a form of graded exercise therapy) and/or cognitive behavioural therapy for all patients with CFS/ME.

Recommendations to the Ministry

- The Directorate cannot, on the basis of the current evidence based review of Professor Kenny De Meirlier's research studies, recommend that public finances should cover expenses for this kind of treatment.
- It is recommended to identify ongoing studies and summary findings from existing research studies on potential causes and diagnostics.
- New research studies and recommendations of interventions have to be seen in relationship to the degree of severity of the disease; mild – moderate – severe – very severe and in relationship to the disease phase the patient is in; unstable – stabilisation phase – improvement phase.



- It is recommended to enhance funding research aimed at causal factors and treatment.
- The facilitation for obtaining and spreading experience based knowledge through regional experience conferences will be done.
- It is under consideration to establish a national treatment and competence service for CFS/ME over a time limited period.
- The Biobank at Oslo University Hospital, Aker, is closely associated with the national service.
- It is recommended to establish ambulant teams for children, young people and adults in all health regions.
- It is recommended to start working to develop good models for how children as next of kin to people with CFS/ME, should be followed up.
- It is recommended to establish an out-patient clinic for CFS/ME in all Health Regional Authorities.
- It is recommended that rehabilitation services based on experiences and competence from Sølvsjøttberget [a rehabilitation clinic where the health personnel over recent years had gained expertise in ME, but which was suddenly was shut down by the South-East Regional Health Authority].
- It is recommended to establish regional Health-Education and Coping Courses for patients and care givers.
- It is recommended to continue the national wide telephone based information service

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The SINTEF Report – published February 28, 2011

Services to patients with CFS/ME in Norway

SINTEF has been commissioned to work out a status report of the health and care services to patients with CFS/ME in Norway.

The main objective of this assignment has been to provide the status for the health and care services in primary and specialist health services to children, young people and those most severely affected with CFS/ME. The report provides an overview over diagnostic tools used in addition to which diagnoses in accordance with the ICD-10 Coding system that are used. The data are based on a sample of 60 municipalities (and three sub areas of Oslo City), 330 general practitioners, all the Regional Health Authorities and the two patient associations. In summary, our investigation allows us to draw the following conclusions:

- There is a lack of knowledge on CFS/ME in the social, welfare and health services. Few municipalities have established services specifically addressing the needs of patients with CFS/ME.
- Some of the Regional Health Authorities have not established any specific service to patients with CFS/ME.
- There is a lack of agreement on, and about implementing diagnostic criteria or CFS/ME.
- There is a lack of curative treatment of CFS/ME.
- There is a lack of appropriate treatment, rehabilitation and caring services to the worst functioning people with CFS/ME
- The plans to establish a service to the most severely affected with CFS/ME at Oslo University Hospital has yet to be accomplished.
- There is a lack of competence and insufficient services regarding the special challenges related to children and young people with CFS/ME.



The main points in this investigation are largely in line with the conclusion drawn in the report from The Social and Health Directorate published in 2007.

Commissioner: The Norwegian Directorate of Health

Translated by

Eva Stormorken

Norwegian ME Association

Eva Stormorken is a member of the Directorate of Health' Expert Panel on CFS/ME. Eva has contributed enormously to the work of the Norwegian MEA over the years, culminating in the events occurring now. She has written several hundred pages since 2005 which have been submitted to the Directorate of Health and other Governmental bodies (in association with other members of the Norwegian ME Association).

LINK SECTION

(links to Norwegian documents and websites)

The website and the original Norwegian version of the letter from Directorate of Health to the Ministry: http://www.helsedirektoratet.no/habilitering_rehabilitering/cfs-me/cfs_me_kunnskapsoppsummering_evaluering_og_abefalinger_til_hod_813684

Letter from the Norwegian Directorate of Health to the Ministry of Health and Care Services: http://www.helsedirektoratet.no/vp/multimedia/archive/00338/Svarbrev_til_HOD_8_338789a.pdf

Commission to the Norwegian Knowledge Centre for the Health Services from the Directorate: http://www.helsedirektoratet.no/vp/multimedia/archive/00338/Bestilling_-_kunnsk_338769a.pdf

Key points – summary of contributions from members of the Directorate's Expert Panel of CFS/ME representing the Norwegian ME Association and the M.E. Network in Norway: http://www.helsedirektoratet.no/vp/multimedia/archive/00338/Innspill_fra_bruker_338899a.pdf

SINTEF's website on ME/CFS:

<http://www.sintef.no/Teknologi-og-samfunn/Helse/Helsetjenesteforskning/Samhandling/Tilbudet-til-pasienter-med-CFSME-i-Norge/>

The SINTEF Report on CFS/ME: http://www.sintef.no/upload/Teknologi_samfunn/ME-rapport.pdf

SINTEF Technology and Society (English information about SINTEF):

<http://www.sintef.no/home/Technology-and-Society/About-SINTEF-Technology-and-society/>

<http://www.sintef.no/home/About-us/>