



April 2007 Newsletter

Welcome to a **Special** Invest in ME Newsletter for April 2007.

Are the ME Dominoes Falling?

Recent news from Norway gives hope that changes are afoot in the way myalgic encephalomyelitis is being perceived and treated.

After much campaigning the results of the Norwegian ME-forening (the Norwegian ME Association - the main support group for people with ME in Norway) is bearing rewards.

On Thursday 29th March Stortinget (Norwegian Parliament) completed a 1 hour and 10-minute debate about ME and what should be done about the situation. This has led to the Norwegian Minister for Health and Care Services announcing publicly a long list of proposals which she stated will be put into action to ensure that ME-patients get proper care.



The minister, Sylvia Brustad, has now engaged herself personally in the case of ME. The health minister is now on record as stating that more knowledge, support, research and funding is required to provide an adequate approach to this illness which is estimated to affect 10,000 Norwegians.



"This is an illness which is difficult to diagnose and treat, and it is an illness to which health services have, up till now, given too little attention. This the government will change, and we will follow this up in the budget process" said minister Brustad.

This is significant as it could have a snowball effect on other countries over time.

Once one European country recognises the true biological nature of myalgic encephalomyelitis and then begins to change its infrastructure (healthcare provision, education, research, funding priorities and public perception) then it will be difficult for other European countries to continue to bow to long-established vested interests in starving biomedical researchers of funding. Other European Medical Research Councils, Medical Officers and Departments of Health will find it far more difficult to maintain an apathetic or biased approach.

Once a model is established for funding proper scientific analysis, using correct guidelines and accepting the need to listen to patients' own experiences then this will have an effect on other countries.

Perhaps the ME dominoes will begin to fall.

Some highlights from the Inquiry report -

- **Reinforce the production and distribution of relevant and up to date information of the illness and of meaningful management and care guidelines for social, health, school and NAV (Work and Welfare) staff.**
- **Reinforce patient organisations' possibilities for distribution of information to patients, relatives and professionals.**
- **Municipalities must offer investigative, management, care and rehabilitation services (institution- or home- based) which take into account the individual needs of the patient with CFS/ME and their relatives. These services must be formulated in multi-disciplinary, individual care plan and must take into account co morbidities, general condition, prevent complications and address educational and professional rehabilitation together with respite care for family members.**
- **Patients with CFS/ME have a need for essential healthcare, if necessary in specialist health services. The health service must ensure there is sufficient investigative, management and rehabilitation services in all health regions.**
- **There must be a focus on the way the illness presents itself in individuals so that symptom-management, general condition, prevention of complications and individual set-up become the central core of treatment.**

- **Teaching hospitals and rehabilitation institutes can be actual arenas for development of specialist services. The municipalities and health services must clarify responsibility and required roles and responsibilities in a continuing management dialogue, e.g. guidelines for habitation and rehabilitation.**
- **Strengthen research within general medicine, biomedicine, physical health and health service research. The research must be carried out both against underlying illness mechanism, triggering factors, and against development of safe and effective diagnostic methods, curative and alleviative management, and care and rehabilitation.**
- **Establish a national competency network for CFS/ME. The network shall ensure a national knowledgebase and publicising of the condition. This becomes central to the issue of CFS/ME becoming recognised as a clinical entity.**
- **It is important that there is close contact within clinical activity, such as also analysis, management and research is carried out within disciplines in the network. The network will be set up to follow international professional development, together with contributing to establishing quality control and establishment of national diagnostic criteria, professional advice and models for good individual patient courses. The network must help to establish a quality benchmark for CFS/ME.**
- **Projects concerning children and young people and the most severely affected must have special priority. A time-limited project for research, knowledgebase building and knowledge distribution about children and young people with CFS/ME must be established in a professional environment with broad clinical and research-oriented experience. The objective for the project must be to raise expertise on all levels in the health service so that result of the project can be implemented by all regional health services.**

Some of these recommendations are similar to those of the Gibson Inquiry -

- calls for this illness to be given due recognition
- calls for funding for bio-medical research
- establishment of a national competency framework
- calls for research into ME to be made a priority

As we stated with the Gibson Inquiry -where we felt it is a relief that at last an inquiry is acknowledging that ME is a severe, incapacitating, illness and that those who suffer from it, as well as their carers and families, may have their lives completely ruined - we now see a similar stance being taken by a European government.

We believe that we must move forward and ensure that people are correctly diagnosed with this illness and that doctors and scientists treat patients knowing and accepting that they have a genuine and serious illness. The positive points from the Gibson inquiry now need support to capitalise on the events occurring in Norway and the challenge now will be to harness the momentum generated by events in Norway to proceed with proper funding for biomedical research and a will to find a cure for this illness. A Pan-European movement needs to be built and we hope to begin that at the International ME/CFS conference in May.

This is an opportunity to benefit ME patients and find a cure for this illness.

Invest in ME is hoping to arrange for the main protagonists in this story to come to the International ME/CFS conference in London in May. Already the president of the Norwegian ME Association, Ellen Piro, will be speaking at the conference on 1st May and several other members of the Norwegian group will be attending also. Ellen has also secured the attendance of other Norwegian medical and research staff at the conference including Professor Harald Nyland, who was knighted in Norway for his work in relation to MS.

"Takk til i alle i Norge for å vise den riktige veien" fra IiME



See Breakthrough in Norway for more details of the news from Norway.

Gibson Inquiry report can be found [here](#).

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