European law proposal:

Rights of people with myalgic encephalomyelitis (ME)

This is a first draft of a law proposal that is currently planned to be handed over to the European Union in autumn 2007.

ARTICLES

§1. Give ME people a fair share of the medical and social welfare system with equal conditions as with other diseases. Also, biomedical research on the condition should be funded with a fair share.

§2. Have at least one ME specialist available in each region of the member countries, respecting the fact that the patients can not travel long distance. The specialist should be a neurologist, internist or immunologist. Preferably there should be a specialist team with a neurologist, internist, immunologist and endocrinologist. For children a paediatric specialist/doctor should be available.

§3. The ME specialists should be active in ongoing biomedical research about ME. For example should they participate in conferences. Preferably, they should be conducting biomedical research on the disease themselves.

§4. The doctors in primary care (generalists) should have at least a one day workshop (8 hours) with several internationally recognized ME specialists and researchers.

§5. University students to become physicians should have at least a three day education (24 hours) with several internationally recognized ME specialists and researchers.

§6. The nurses in health care should have at least a one day education (8 hours) about ME.

§7.The doctors working with urgency and/or operation should have at least a three day workshop, with several internationally recognized ME specialists and researchers. Especially issues as anaesthesia, medication sensitivities, immune dysfunction, cardiovascular system and slow recuperation rate, should be treated. As well as other issues as special needs of patients as need for silence and rest in order to recuperate.

§8. Assure that a patient with suspected ME, should have immediate access, within two weeks, to the ME specialist team because early diagnosis is the most important mean for achieving a low degree of disability of the patient. Some that are diagnosed early, even have a chance to improve completely. The earlier the diagnosis, the higher the rate of recuperation and the lower the rate of high degree of disability.

§9. Assure that the ME patients have social protection. With work disability pension. Necessary adaptations depending on degree of disability: aid with household, shopping, child care, work, etc.

§10. On all deceased people with ME, that have agreed to it, autopsy shall be performed and tissues shall go to a tissue bank in order to support research on the condition.