Invitation from the Danish Insitute for Human Rights to Dansk ME Forening to participate in panel discussions regarding how well and effectively the UN Disability Convention has been implemented in Denmark, and an invitation to the launching of a new web site on February 28th 2012

Over the last decade complaints about the way disabled, ill and old people are treated by the health and social system in Denmark have increasingly been sent in by different handicap organizations and private persons involved. Nothing has happened to better this situation. On the contrary, national economic problems have been used as an excuse for constant cut downs. This is what it is - but at the same time a tendency to treat the clients in a most cruel and humiliating way has found its way to our system. This is not solely a problem for ME patients. Several other groups of handicapped are experiencing the same thing.

This was our situation, when we in May 2011 received an invitation from the Danish Institute for Human Rights http://menneskeret.dk/forsiden to participate in 5 panel discussions together with 130 other Danish disability organizations, questioning how well and effectively the UN Disability Convention has been implemented in Denmark.

We were honored by this invitation since no other ME or ME/CFS related group in Denmark were invited. We found it important to accept this invitation, because this way we could point at some important flaws in implementing the UN Disability Convention in Denmark and at the same time make ME known as an organic debiliating disease.

As it turned out, the dates set for these panel discussions were identical to the dates set for the ME/CFS Conference and EMEA Annual Meeting in London last year, so we asked the Institute for Human Rights, if they could suggest an alternative way for us to comment as we found this very important to discuss. They immediately suggested that we send in our written comments, which would be included in the panel discussion material. Comments from all 28 participating handicap organizations would, at a later date, be added to a brand new web site on the UN Disability Convention.

When asked, the Institute for Human Rights answered that the initial idea for this project was to first analyze the overall situation in Denmark, regarding the implementation of the UN Disability Convention, and after that to take up any crystal clear violations of the Disability Convention - or of Human Rights for that matter - for further investigation.

We thoroughly went through all the articles in the UN Disability Convention, and added our comments at the end of each article relevant to us. We were determent to point at the fact, that although the diagnosis ME was legally and officially registrated in Denmark, the Danish Board of Health continued to claim that ME doesn't exist, and also accepted the general practice of GP's of giving other diagnoses in stead of ME, allowing psychiatry to take over. We attached three personal ME patient stories to verify our comments.

Two and a half month later, in August 2011, the Institute for Human Rights contacted us again and informed us that they found the content in our comments under Article 23 (about Respect for family and home) worrying. They would now like us to deepen our comments further and also produce a 2 minute video as documentation.

A family with a daughter who has been seriously ill with ME for the last five years were willing to give an interview. What this family has been going through, caused by their GP, hospitals, therapists and health and social authorities goes beyond imagination. It does represent violation of both Human Rights and the UN Disability Convention.

Our short video and our comments were very well recieved by the Danish Institute for Human Rights.

On our part, we would like to add, that it has been a very pleasant and constructive experience to cooperate with the Institute, and in the most friendly and obliging atmosphere.

On February 28th the launching of the new web site on the UN Disability Convention took place, and we were invited to attend this event to see our comments and video being published.

www.handicapkonvention.dk

To see our comment: write ”artikel 23” in the Search box on top of the site, click on the paragraph with our name in it (Dansk ME Forening) and this should get you directly to our comment. We have made an English translation right below:

Dansk ME Forening's comment on Article 23:

What are in your opinion, the biggest challenges within the area covered by Article 23?

Basically we consider the biggest problem to be the focusing on politics and money at the expense of a decent view on human nature, morals and ethics. In our case this means the decisions made by health authorities and politicians that ME is a functional disease that only exists in the head of the patients.
The responsibility and struggle that adults, children and adolescents suffering from this disease has to overcome is solely resting on their shoulders only, because - the ***GP*** *in general does not know what this disease really is about* ***– school is a*** *place where parents for years have to fight to provide their ME sick child tailored tutoring, because the child, due to illness, for periods, or maby all the time, has great difficulty attending school, if the considerations necessary are not provided –* ***medical specialists*** *do not understand the seriousness of this disease and often cannot agree on which diagnosis to give* ***– the hospital physicians,*** *who renounce the severely ill ME patients, children and/or adults, because they do not dare to take the responsibility for such ill patients and therefore initiates sectioning to a psychiatric ward, believing the parents are the problem in the case of children –* ***nursing staff in hospitals and home nurses*** *whose working routines cannot embrace the special needs ME sick children and adults have –* ***the municipality*** *that refuses to provide special help og aids to children/families* ***– caseworkers*** *who are much too eager to initiate sectioning of children with ME, especially if the parent is single.*

What do you suggest Denmark need to do to solve these challenges?

We would like to encourage the national health authorities and the politicians to

- to adapt to their own classification of diseases – (in this case the classification published by the Danish Board of Health, based on the WHO ICD-10.

- to let go of unfounded prejudice towards this disease and take information on this disease from people with many years of experience or parents to children with this disease seriously, so that children, adolescents and adults, suffering from this disease, can be met with respect and decent treatment, and receive the practical help and support they need in order to be able to have a full life. Prejudice or lack of money should not be used as an excuse to section children or adults with this disease or to omit to provide the tutoring or education needed for the sick child.

- to initiative serious special education for physicians, nurses, carers and staff at social and health offices regarding treatment, nursing and caring for the seriously ill ME patients and their families, including children with ME, and also offer special courses for teachers, school nurses, school psychologists and educators on the handicaps these children suffer from.

> *[Next is the video showing an interview with a family with a severly ill 23 year old daughter, who have been dragged through almost everything terrible, you can think of – and then a little more]. The video is subtitled in Danish.*

Also this meeting was an encouraging experience. Several politicians, including the Ombudsman, attended this meeting and overheard the conclusion made by the Institute for Human Rights, namley that Denmark has huge problems to quite fulfill the implementation of the UN Disability Convention.

As it appears in our comment above, the overall problem seem to be – not so much the economical problems in our country – but the way the lack of money influences many of those imployed by the authorities to treat disabled clients in a disrespectful way, as though they aren't worthy of a the respect that is due as human beings – and this despite the fact, that they have paid for these services throughout their entire life through taxes to the state.to decent approach or the decent treatment, they are entitled to as human beings.

We have in many ways a very fine and comphrehensive health and social system in Denmark, but ethics and morals seem to have walked out the backdoor because of a still growing economic crisis. In stead of helping and supporting disabled people, the state has demonstrated a tendency to ”take over” and get paternalistic. And unfortunately, for many of our seriously ill ME patients it is a fact, that they have been made worse, because they haven't received the help they are entitled to or the wrong kind of treatment has been forced on them.

The Institute of Human Rights are determined to change this. Society should follow up the terms they have accepted by signing the UN Disability Convention. It is NOT the other way around.

We will keenly follow the independent work of the Danish Institute for Human Rights as well as participate in this as much as possible. If our comment appear to have played a role in some important changes in Denmark, we will certainly be very pleased, because ME patients will benefit from this too.

And who knows? Maybe the proposals for improvement, made by the Danish Institute for Human Rights, will be recognized in other countries as well, and contribute to changes in other countries.

Best wishes
on behalf of the Board of the Danish ME Association

Lajla Mark
Chair