

INTRODUCTION TO THE POPULAR LEGISLATIVE INITIATIVE ON HEALTH SERVICES FOR FIBROMYALGIA AND CHRONIC FATIGUE SYNDROME IN CATALONIA (SPAIN)

May 2007

Catalonia, an autonomous region of Spain, has a population of 6 million. The prevalence of FMS and CFS is thought to be similar to that of other developed countries (2.4% and 0.5% respectively). The people in Catalonia affected by these illnesses are severely neglected by the Catalan Public Health Services. At the moment, to access one of the few specialists in these illnesses, the waiting lists are between one and three years (and these waiting lists are closed at the moment). The Catalan Health Department proposed a plan (Nou Model) in 2006 in which those who might have these illnesses would have to be attended to in Primary Health Care (PHC) only. Unfortunately, PHC doctors are not trained in these specialized and complex illnesses (many do not believe these illnesses even exist) and they do not have permission (budget) to do any relevant tests. Also PHC doctors have been fighting, for years, to have at least 10 minutes per patient as opposed to the 5 minutes they have now.

A person in Catalonia with symptoms of FMS or CFS, at the moment, goes on a “medical pilgrimage” trying to find out what is wrong with them. Once they find a doctor that suspects it might be FMS or CFS, they can get on a two to three year waiting list. Meanwhile, their health, their job situation, their economic situation, their social and family life go into crisis. Once the patient has a diagnosis (treatment is not really an option as the Public Health Care system does not have the funds for that), they will begin the “legal pilgrimage”, as the ICAM, the Catalan Medical Evaluation Board, does not take FMS nor CFS seriously, i.e. they do not even look at the medical reports from the FMS or CFS specialist (there are endless documentation on this). So the patient has to hire a lawyer and start the long, two year process through the courts to try to get sick leave or disability if that is what the specialist has recommended.

At the moment in the Catalan Public Health Care System, there is only one CFS unit in Catalonia (which is also the only one in Spain) and a half a dozen individual FMS

or CFS specialists of various levels of training and competence. There is also a Private Health Care System, in which there is one CFS-FMS unit and a few individual specialists. All Catalonians pay for the Public Health Care System. The private services are beyond the economic means of most people.

Also, the half a dozen FMS and CFS specialists in the Public Health Care System, have their own private offices to which they refer their public patients in order to bypass the waiting lists (and increase their earnings?). This is not “legal” but it is done, everyone knows about it, including the government and nothing is being done.

The Catalan Government’s proposed 2006 FMS and CFS plan (Nou Model) to keep FMS and CFS patients in Primary Health Care, is an obvious attempt to keep patients from having proper medical reports which is the only way to have a minimal chance that, in the “legal pilgrimage”, a judge will give the patient sick leave or disability. With medical reports from PHC, the judge will throw the case out of court. Therefore, it is obvious that the Government’s Nou Model is an attempt to put FMS and CFS patients in limbo and avoid the economic costs of pensions.

Until now, FMS and CFS patients in Catalonia have been making efforts to build associations and to voice their problems (very high suicide rates amongst the people on waiting lists). This has had minimal success and it has been subject to much harassment, manipulation and all-out threats from the government, the government-run FMS-CFS foundation, private foundations and other interests. There has been no interest in the part of the government to dialogue. (Please, keep in mind that Spain is a very young “democracy”, and what might be part of a democratic process in other countries, might be completely unknown or rejected here). The present Catalan government has used the FMS-CFS issues in the last two Catalan elections and has trusted that “groups of women” would not be able to organized themselves in effective manners.

Many attempts were made, since 1999, by FMS or CFS associations to bring their plight to Parliament concerning services, but with not much success. This is why, in 2007, the FMS and CFS associations in Catalonia have united, a historical move, which required a lot of work and which has been met with a very strong backlash from government and foundations. United, the associations decided to carry out this very

massive project: a Popular Legislative Initiative (PLI).

The PLI consists of first writing a proposed law (this requires months of work with lawyers experts in Parliamentary matters) and having all the associations agree on the content. Then the Parliament's Table has to approve that the process can begin. The next step is the swearing in of the signature gatherers (150 ill people went to Parliament to do this in a very impressive event). Then 50.000 signatures have to be gathered. (We are now, as of May 24, 2007, after only one month of signature gathering, at the point of finishing the signature gathering process for which there are four months allowed). Then the law enters Parliament and it is discussed and voted on.

This all sounds very democratic and good. But the reality is that from the beginning of this PLI, the patients' representatives who are leading the Initiative, known as the Promoting Commission, have been meeting with all political parties, tendencies, members of parliament to discuss how they will position themselves. At first it seemed that the government (the government is made up of a coalition of three parties).was against it (naturally) and the opposition supported it (naturally). All this made sense.

But now things have taken a very interesting turn. Although not all members of parliament say it in a direct manner, but they are communicating to us that the problem is not so much services and pensions for FMS and CFS (which was their original worry). The problem now is that they realize that if this PLI goes through, soon other groups (handicapped, homeless, etc) might also want to do PLIs. And as one parliamentarian so well put it: "We can't open up Pandora's Box". Real democracy is threatening.

Mind you, the fact that PLIs exist in Catalonia is a fact that all parliamentarians brag about. But up to now, the PLIs that have been carried out have been on small matters such as that Catalonia be allowed to have a soccer team play in the international competitions, that Spanish be taught one more hour a week in Catalan schools, and that there be day-care for children from 0 to 3 years-of-age (this would seem like an important PLI, but it was not problematic as it was agreed on before hand, so it was mainly used as a public relations move for Parliament to boast).

Right now (May 2007), all parliamentarians want to "negotiate" with us: i.e. they want us to stop the signature gathering, not enter this law in parliament for vote (it could make them look bad when Catalans see how each member of parliament votes) so as

not to open “Pandora’s Box” and in exchange they will give us a few CFS-FMS units. This is out of the question for us. But it is clear that the massive positive response from civil society (in the first month of the four months we have to gather the signatures, we have pretty much gathered the 50,000 required) is a message that a law is needed (we have tried to get services through other means and it has not worked). The thousands of people that have signed the PLI have not done so so that we negotiate some watered-down deal in the hallways of Parliament. It is clear to us that our mandate is that this proposed law enter parliament and be discussed and voted on democratically (and we are very eager to see how those members of parliament who have said they support us, vote).

We realize that we, the FMS and CFS activists in Catalonia, are doing more than we thought we were doing: we thought we were working towards getting much needed FMS and CFS services. But now we realize that we are spearheading a major change so that other parts of civil society that are living injustices might be heard. We did not foresee this nor did we have any intention of creating this very important historical moment. We have enough with our own demands and our bad health. But sometimes, amazing things happen.

One thing is very clear: this is becoming the most empowering process that FMS and CFSers in Catalonia have ever had. Muchly needed.

After the summer the law will probably enter the Catalan Parliament and then a new phase will begin. Keep in touch to see how it all works out!

Clara Valverde, for the PLI Promoting Commission

“They did it because they did not know it was impossible”

For more information on this PLI, see the web (in Catalan): www.ilp-fm-sfc.info

Email in English: formacionsalud@hotmail.com

Also see the PLI on Youtube http://www.youtube.com/watch?v=_ffgx9S40Lg

PROPOSED LAW FOR HEALTH SERVICES IN CATALONIA, SPAIN, FOR FRIBOMYALGIA AND CHRONIC FATIGUE SYNDROME

**TEXT OF THE POPULAR LEGISLATIVE INITIATIVE (PLI) ON FMS AND CFS
March 2007**

Submitted to Parlament by the PLI Promoting Commission (Interested Citizens)

ARTICLE ONE

The goal of this law

The goal of this law is to establish and put into regulation health services that can give adequate management of Fibromyalgia (FM) and Chronic Fatigue Syndrome (CFS) by the Catalan health care system, and the establishment of special measures to improve the services for these illnesses.

ARTICLE TWO

Specialized hospital units (SHU)

- 1. The diagnosing and treatment of FM and CFS in the public health care system will be the responsibility of these specialized hospital units (SHU).*
- 2. The SHU services for FM and CFS shall be composed teams of internists, rheumatologists, neurologists, endocrinologists, and also a psychologist, physiotherapist and nurses.
In these units there will also be pediatricians in order to attend children who have FM or CFS.*
- 3. The establishment of the SHU units for FM and CFS has to be done by order of the Catalan Minister of Health, who will make sure that the services are covered by region, by personnel and will make sure of the proper functioning of these units.*

ARTICLE THREE

Number of SHUnits

*A minimum of eight units for FM and CFS are to be established in the Barcelona Health Region and at least, one unit in each of the other health regions in Catalonia, which shall be equipped with resources and means for diagnosing and treating FM and CFS.
One of the units should be established as a Center of Excellence (research) and its objective will be to centralize and carry out research on diagnostic tests and efficient treatments. The setting up of all these units will have to be done in the year after this law is passed.*

ARTICLE FOUR

Access to SHUs and waiting lists for FM and CFS

- 1. All patients have to have access to the SHU units for FM and CFS right from the moment their symptoms of the illness are detected.**
- 2. Under no circumstances shall a patient with FM and/or CFS have to wait more than 90 days on the waiting lists of these units, in order to avoid risks, uncertainty and unnecessary suffering, and also so that the patient does not get worse and to avoid useless treatments and unnecessary use of social and economic resources.**

ARTICLE FIVE

Primary Health Care

When a Primary Health Care (PHC) doctor sees a patient with what could be FM or CFS symptoms, he or she shall refer the patient to one of the specialized FM and CFS units. Thereafter PHC will collaborate with the FM and CFS units in the follow-up of the treatments prescribed by these units and the intervention in PHC will be multidisciplinary (family doctor, nurses and social workers).

ARTICLE SIX

Training

Specific training programs will be set up to train doctors on these illnesses so they can work in the CFS and FM units. There will also be training for PHC teams. These training programs have to give credits to the participants and shall have a duration of at least 12 hours. The training is to be given by internationally recognized specialists.

ARTICLE SEVEN

Disability and medical evaluations

- 1. Those diagnosed with FM and/or CFS have to have access, through the administrative route, to disability status when it is relevant and also to the economic and social support they are entitled to, based on the medical reports and the diagnostic tests carried out by specialists in these illnesses.**
- 2. The ICAM (Catalan Medical Evaluations Board) or the body with competence to do medical evaluations, in the case of FM or CFS, should take into account the diagnosis, medical reports and recommendations given by the hospital units which are specialized in FM and CFS and shall make a decision on the basis of this information..**
- 3. If the ICAM requires the person with FM or CFS to undergo an extra medical evaluation. this shall be carried out by a specialist in these illnesses or by a center accredited to diagnose and treat FM and CFS..**