



8 September 2015

REGARDING PETITION P-04-587

PETITION FOR A SPECIALIST SERVICE FOR PEOPLE WITH ME/CFS

The current situation for people with ME/CFS in Wales.

As you are aware, **MESiG** previously presented a Petition to the Assembly for a Dedicated Support Team for ME/CFS and Fibromyalgia Sufferers in South East Wales since there has been no-one to diagnose or confirm the condition beyond their GP, or to provide effective treatment. The all-Wales ME/CFS and Fibromyalgia Implementation Group and the appointment of ME Champions for each of the Health Boards in Wales is a sign that these conditions are being taken seriously and require quality medical intervention. We are very concerned that the process is very slow and the effect is not yet reaching the people who have ME/CFS, or medical staff who are in contact with them.

We understand that Cardiff and the Vale has not yet been able to fill the position of ME Champion/ Lead for ME.

MESiG is based in the Cardiff area but we have no-one to whom we can address our concerns and we continue to be contacted by people who have all the symptoms of ME/CFS but who have no diagnosis and GP services which have no training or knowledge of ME/CFS. Also there is still no-one to whom GPs can refer ME patients, even if they have been able to provide a basic diagnosis. Therefore the current plan for ME/CFS for Wales is not yet meeting any of the basic needs.

We note that Dr Graham Shortland, Medical Director and Fiona Jenkins, Director of Therapies are involved in dialogue. We would like to have further information about this as it is not clear to us exactly what is being planned and what the connection is with Velindre NHS Trust in regard to the appointment of a medically qualified lead as ME Champion. How is this person being sought? What are the criteria for the selection of this person? Will the suggested co-coordinated approach involve people who are specifically trained to cater for people with ME? Will anyone involved be looking at the latest research on ME or be open to looking at the latest findings?

We also remain unaware of the identity of the ME Champions for each of the Health Boards around Wales. Who are these Champions and what is their training in regard to ME? Because **MESiG** directly supports people who have ME, running Support Meetings every month, visiting them in their homes, assisting them with Benefit Claims etc, we have been asked by various Health persons, Social Services and Advocacy Groups in different areas of Wales to identify these Champions for them, since they cannot understand this complex condition or meet the needs of ME patients without input from the Health Boards. This has been the case in Torfaen, Haverfordwest and Tonypany. Lack of understanding has resulted in some severely sick people being bullied, and their actual medical needs being neglected since there is a lack of awareness of ME's various symptoms, the fact that it is a Neurological Condition, that it fluctuates and that it may affect people mildly, moderately or severely.

We have been called into emergency situations with people who are critically ill since there has been no-one medically qualified available with any understanding of their condition. The only 'treatment' offered to them has been 'rehabilitation' that when taken up has made them much worse. They are bed bound, incontinent, have difficulty taking nourishment yet are expected to respond to further periods of rehabilitation and denied such things as incontinence pads or even intervention by a Continence Nurse. They, their families and Carers are told that this is not necessary since they are able to get out of bed and use the toilet (i.e. their condition is not accepted and their inability is disbelieved).

MESiG is asked for input in a variety of situations including one Medical Practice where their GPs are not only not trained to diagnose ME/CFS, they also refuse to refer patients on to either Neurology or Rheumatology, because the Practice does not accept that the condition exists, let alone that it is a Neurological condition. One of their Doctors stated that the World Health Organisation is incorrect in saying that it is a Neurological condition and that Mark Drakeford is not a Doctor, hence they are not prepared to accept the condition. This has resulted in poor medical treatment, severe distress for patients, refusal by Capita to allow PIP Benefit for one woman because of the lack of medical confirmation/reports, and the necessity for her to move to another GP Practice further from home.

In Cardiff and the Vale, one person diagnosed with ME, who had previously attended a Neurological Clinic, asked to be referred back to a Neurological Clinic but their GP was informed that the clinic is no longer seeing people who have ME. Another person waited many months to attend a Neurological Clinic but when he attended he was told that the Neurologist was away and a nurse with no knowledge of ME was running the clinic that day. Later his GP was informed that he had been discharged from the clinic.

In an informal meeting with a Senior Neurologist in Cardiff, we were advised that what people with ME really need is a Specialist Clinic that offers the full range of services required by someone with ME since there are so many aspects to the condition. She herself runs a clinic but would not identify it as an ME clinic, since she would be over-run by people seeking help, even though she quietly sees people who have ME in that clinic (and she is asked to visit other areas of Wales to provide advice regarding young people

with ME because there is no-one in their locality to provide this). Despite her high position in Neurology in Cardiff and the Vale she had not heard of the Task and Finish Group or ME Champions, but said that whoever is put in place would need to be proactive not just in the position. This was striking for us, seeing that we have identified and repeatedly highlighted this need for a Specialist Service, as this medical professional suggests.

The model for an ME Clinic already exists in England. It works extremely well, providing co-ordinated support and treatment. One of our **MESiG** members had a very good service from it when he lived in England.

We at **MESiG**, and the members we are supporting, look forward to a positive outcome.

Regards

MESiG