

Our Ref P-04-587

Your Ref MD/01067/15

Date 18.5.2015

Dear Sir/Madam

*Response to Mark Drakeford's letter dated 16.4.15*

Apologies for not responding before committee date on 12.5.15. We didn't, for some reason, receive your email until after the deadline.

Following on from our previous correspondence, we are sad to report that the woman with ME we referred to, has died. She required urgent medical treatment that could take into account her needs as a person with ME. Instead she suffered at home in a totally unsuitable situation, in pain, fear and isolation. She was finally found unconscious, taken into hospital and died a week later. We are now in touch with two more people who have severe ME, in similar critical unresolved situations. They do not have time on their side to wait for Services to catch up with their needs.

Last week we were disappointed to hear that Cardiff and the Vale Health Board has not yet appointed a Champion for ME. It is ironic that in the very area of Wales where we have been asking for an ME Clinic and a dedicated Team for ME, no-one has been appointed to be an ME Champion. It is sad that Cardiff, the Capital of Wales and the Mecca for medical expertise is not able, in this regard, to keep up with most of the other Health Boards in Wales.

We are aware of the Neurological Conditions Plan. However, although you state that ME is included under Neurological Conditions and therefore the Plan, we have recently heard that ME patients are not to be seen by Neurology Clinics in Cardiff. For example, one patient referred to a clinic last year, waited 6 months but the Neurologist was absent on the day of the appointment. He was subsequently removed from the Clinic's list. Another patient was recently refused an appointment via her GP, "as the Neurology Clinic is no longer seeing patients with ME". Other ME patients are not being referred on by their GPs (even if they are unable to recognise or give a diagnosis of ME themselves).

It is unclear to us what the actual role of these Champions for M.E. will be, once they are in place. Will GPs be able to refer patients to see them at a Clinic or will they educate others about the condition?

Yours Sincerely

Miriam Wood (MESiG board member)