

PE1408/Y

Petitioner Letter of 24 November 2015

Scottish Parliament - Petition: PE 1408

Petitioner - Mrs Andrea MacArthur

24th November 2015

I have been notified that the Petitions Committee intend to meet again on 1st December and I would like to make you aware of the following information.

As you will know, the committee were waiting to hear from the Scottish Parliament on what was agreed at the recent Diagnostic Steering Group meeting. The purpose of this meeting was to hopefully compile a draft form of guidelines suitable for clinical use. I gather the meeting took place on 17th November but I have not, as yet, been informed of what resulted from it. For this reason, there is nothing new to report to the petitions committee as I am not in a position to comment until I obtain sight of these guidelines. However, I do not want to lose the opportunity to comment on them before they are finalised, as happened with the BCSH Guidelines, and would ask the committee to ensure that the Scottish Parliament are asked to continue to liaise with the Diagnostic Steering Group so that I can have the opportunity to view these draft guidelines as was promised.

Since submitting the petition in 2011, the number of patients contacting our group continues to escalate at an alarming rate. When I last wrote to the committee, the number of members on our group alone was approaching 5,000. In just 11 months, that figure has almost doubled and the majority of the members are from the UK. These are not people just wanting to engage in some social conversation about PA – they are sick and distressed patients struggling on what little, if any, treatment they are receiving.

I hope the seriousness of this situation can be emphasised upon all those in the position to do something about it. The time has come where this issue must finally be recognised and addressed and I hope that the various political and health departments responsible for these matters will now accept this and work with us to bring about the necessary changes to the understanding and treatment of the condition.