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Mr David Stewart MSP
Convenor
Public Petitions Committee
Scottish Parliament
Edinburgh
EH99 1SP



5 February 2014

Dear Dave,

SCOTTISH PARLIAMENT PUBLIC PETITION PE1463 ON EFFECTIVE THYROID AND ADRENAL TESTING, DIAGNOSIS AND TREATMENT

Further to my appearance at the Public Petition's Committee on 1 October 2013 I now write to set out the work the Scottish Government has been progressing on the above petition and the consideration of whether the Scottish Government would set up a Short Life Working Group (SLWG) to examine all of the available clinical evidence on the treatment of patients suffering from thyroid and adrenal disorders.

As mentioned at the Committee the Scottish Government was awaiting responses from the British Thyroid Association, the Scottish Clinical Biochemistry Managed Diagnostic Network (SCBMDN) and The Scottish Health Technologies Group (SHTG). These responses have now been received and all indicate that there is no evidence base to support the changes being sought by the petition. On this basis the Scottish Government has no plans to set up a SLWG.

However, we are sympathetic to the experiences of the petitioners and others who find themselves unable to obtain or access a diagnosis or a treatment they feel should be available. We will therefore commission a piece of work to explore how patients understand and feel about their quest for a diagnosis and/or treatment in areas where the evidence is limited, the science is uncertain or disputed and/or where a condition is rare or obscure, or not widely recognised. This will include a listening exercise with patients and also with staff dealing with patients with such experiences. The aim of this project is to help illuminate the concerns and perceptions of patients in such circumstances and so support efforts to improve communications and patient engagement.

I hope that this sets out the Scottish Government's commitment to engage with patients and staff to look into this further.

MICHAEL MATHESON