PE1577/O

Petitioner's submission of 22 February 2018

I met with the Team Leader – Strategic Planning and Clinical Priorities Team (Scottish Government) on the 26th of January 2018. Murdo Fraser MSP was also in attendance. We discussed the main issues in my petition and it is positive that I am now engaging in discussions with the Scottish Government. There are several projects and evidence gathering exercises taking place at the moment. The National Advisory Committee for Neurological Conditions (NACNC) are developing a National Action Plan on Neurological Conditions. The lived experience project is based upon qualitative research commissioned by the Health and Social Care Alliance. There is also a neurological services mapping exercise, as well as neurological engagement projects and quantitative research. The Scottish Government will launch a programme of engagement over the summer months and launch their consultation on the draft National Action Plan in the Autumn.

I have been asked by Health Improvement Scotland to become a member of the Development Group for the Review of the General Neurological Standards for Care and Support. I have accepted this position and look forward to working on this review and raising awareness of Cerebral Palsy as an adulthood condition. While the research and the National Action Plan for neurological conditions are welcomed, these are at an early stage of development. I know a care pathway for adult Cerebral Palsy NHS services will not be developed overnight but the issues raised in my petition have not been solved, and I would ask the Public Petitions Committee to monitor the Scottish Government's commitments regarding the petition closely. I should receive regular correspondence from the Scottish Government and hope to develop a good working relationship with the team leader and his team. We are a long way from providing the quality and continuity of care that adults with Cerebral Palsy in Scotland need and deserve. I would like to see a lot more progress and positive results as I do not want to be submitting the same petition in 5 years' time because there has been no movement from the status quo.