

New All Party Parliamentary Group launched to bring political attention to the rare disease PKU

Thursday 8 March, 2018

Wednesday 7 March 2018 marked the launch of a new All Party Parliamentary Group (APPG) which has been established to examine the issues facing people living with the rare metabolic disease phenylketonuria ("PKU").

PKU is a rare genetic metabolic disorder affecting around 1:10,000 people in the UK. People with PKU cannot metabolise phenylalanine, an amino acid found within protein foods. Currently, the only treatment funded in the UK is an extremely restricted dietary therapy in which almost all natural protein is removed from the diet. The majority of PKU patients in other European nations have access to the drug BH4 (Kuvan). The NHS does not currently commission Kuvan treatment.

Chaired by Liz Twist, MP for Blaydon, the APPG will raise awareness of PKU and consider the need for improvements to access to treatment.

Liz Twist said "A local family in Blaydon contacted me to explain their concern that their young son with PKU must eat virtually no natural protein to ensure safe brain development even though there is a drug treatment – Kuvan - which would help him. Kuvan is used in almost every other country in Europe but is not provided by the NHS. I am very pleased that this APPG has been formed with cross party support to examine the barriers and difficulties faced by people living with PKU."

Eric Lange, Chairman of NSPKU, the national charity for PKU, said "The NSPKU is delighted to be working with the APPG to raise awareness of PKU. Many patients and families living with PKU have felt ignored and neglected for too long. We are extremely grateful for the support of MPs for bringing political scrutiny to our concerns."

Notes to editors:

- The APPG includes the following members : Liz Twist, MP for Blaydon (Chair), Christina Rees, MP for Neath (Vice-Chair), Kwasi Kwarteng, MP for Spelthorne (Vice-Chair), and Neil Gray, MP for Airdrie and Shotts (Vice-Chair).

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Related Keywords:

PKU :: Phenylketonuria :: Kuvan :: Rare Disease :: APPG ::

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