MPs have been challenged to follow the super-restrictive diet for the disease PKU

Thursday 28 June, 2018

Three year old Stanley Brown is one of about 2000 children in the UK who have phenylketonuria, (PKU for short), a metabolic disorder which is diagnosed in new-born babies by the heel-prick test. People with PKU have an enzyme deficiency which prevents them from processing protein properly. As a result, children like Stanley have to eat a diet containing almost no protein. Meat, fish, dairy foods and eggs are banned, but also everyday foods like bread, pasta and rice need to be severely restricted. If children stray from their strict diet they risk irreparable brain damage. The diet needs to be continued throughout life.

Stanley's family and many other people living with PKU have challenged their MPs to follow the restrictive diet for a day.

Stanley's mother Jessica Brown of Halesowen says of the challenge: "The PKU diet is incredibly hard and complex and MPs are going to find it a shock. Even vegetables need to be restricted. Eating out and spontaneity is virtually impossible and the impact on childhood and family life is hard to measure." Jessica is very frustrated that a drug treatment for PKU called Kuvan is not available in the UK. Kuvan would help Stanley have a more normal diet whilst protecting his brain development. The NHS is due to re-evaluate the funding of Kuvan this year.

The diet challenge takes place on International PKU Day on 28 June which is a working day in the House of Commons. Conservative MP James Morris will be taking up the challenge on behalf of Stanley who lives in his constituency of Halesowen and Rowley Regis. Liz Twist who represents the North-East constituency of Blaydon is taking up the challenge on behalf of her 12 year old constituent Archie. Her entire office staff will be joining in too. Her Labour colleagues Ian Austin of Dudley and Nick Thomas-Symonds of Torfaen will also be following the dietary regime to support constituents with PKU. MPs have been tweeting about their problems finding food to eat through the day.

Liz Twist said "A family in my constituency explained the difficulties of living with PKU and their frustration that the UK lags behind the rest of Europe in adopting the modern treatment Kuvan. PKU is an invisible condition that is not well understood. This one day diet challenge will give MPs a small taste of living with this difficult regime, which our constituents with PKU must deal with every day for their whole lives."

James Morris said "My constituents Mr and Mrs Brown face the constant worry of managing their son's rare condition PKU. I am taking up this challenge of following Stanley's dietary treatment for PKU to raise awareness of this difficult condition."

The House of Commons challenge was preceded by a Parliamentary debate in Westminster Hall on 26 June, designed to explore the unmet needs of patients and families with PKU and the barriers to adopting new treatments for PKU. Liz Twist has formed a cross party group of MPs to improve care for people with PKU.

Professor Anita MacDonald OBE, consultant dietician at Birmingham Children's Hospital and a world expert on this inherited metabolic disorder said: "I have treated children with PKU for decades and I have seen first-hand the impact it has on children, their parents and wider families. The struggle often continues into adulthood. I am very grateful that MPs are taking up the diet challenge to try and understand the difficulties of this condition. I think they will find it harder than they would imagine." Professor MacDonald will also be hosting an event at Birmingham Children's Hospital on 29 June for children with PKU to meet the MPs who have followed their diet.

Notes for editors

The diet challenge (#PKUDietChallenge) is organised by NSPKU, the national charity for PKU. It is taking place on 28 June.

Participants are:

Liz Twist (Labour, Blaydon) and her staff

Related Sectors:

Charities & non-profits :: Children & Teenagers :: Food & Drink :: Health :: Medical & Pharmaceutical ::

Related Keywords:

PKU :: Phenylketonuria :: Kuvan :: Rare Disease :: Diet ::

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James Morris (Conservative, Halesowen and Rowley Regis)

Neil Gray (SNP, Airdrie & Shotts)

Vicky Ford (Conservative, Chelmsford)

Nick Thomas-Symonds (Labour, Torfaen)

Ian Austin (Labour, Dudley North)

Liz Savile Roberts (Plaid Cymru, Dwyfor Meirionnydd)

Stephen Morgan (Labour, Portsmouth South)

Peter Aldous (Conservative, Waveney)

James Cartlidge (Conservative, South Suffolk)

Christina Rees (Labour, Neath)

Many healthcare professionals, including a team of 10 biochemists who provide the new born screening service for London.

The Director of Dudley Zoo, and many other colleagues, friends and family of people living with PKU.

A debate on PKU took place at Westminster Hall on 26 June 2018.

An event for MPs who have followed the diet to meet children with PKU will take place at Birmingham Children's Hospital on 29 June. Contact NSPKU for invitation details.

PKU (or phenylketonuria) is a rare genetic condition affecting about 1:10,000 people in the UK. It is caused by an enzyme deficiency leading to an abnormal chemical build-up of an amino acid (a building block of protein) called phenylalanine. The drug treatment sapropterin (Kuvan) was licensed in 2008 and is used as a standard treatment for PKU in the majority of countries in the EU.

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