

Press Alert - Midlands MPs support children with rare disease by following their super strict diet

Wednesday 6 June, 2018

MPs from all political parties are following up a planned debate in Parliament on access to medicines and support for the rare disease PKU by following their restrictive protein free diet.

MPs will be eating a super restricted diet on a working day in the House of Parliament to support children with the rare disease PKU on International PKU Day on 28 June 2018. The event follows a cross party debate on 26th June on access to medicine and other concerns raised by people with this metabolic disease. MPs from the Midlands region will subsequently attend a "PKU Question Time" event at Birmingham Children's Hospital in which they can ask MPs about how they managed their diet challenge.

Why is this event important nationally and for the Midlands?

1 in 10,000 babies are diagnosed with PKU at birth. They cannot metabolise protein properly and must eat a diet devoid of almost all protein to develop normally. This diet must be maintained for life. The diet treatment was invented at Birmingham Children's Hospital in the 1950's and now patients want access to new modern treatments to help them cope. James Morris MP will be attending the "PKU Question Time" to meet his constituent: three year old Stanley Brown from Halesowen. The event will be attended by other local families, clinical experts and MPs. Ian Austin, MP for Dudley, will also be speaking at the debate and following the diet challenge.

Diary dates

26th June: House of Commons, Westminster Hall debate commences 9.30 am – open to press, briefings from national charity NSPKU will be available.

28th June – International PKU Day – MPs will be following and tweeting #PKUDietChallenge

29th June – MP's PKU Question Time – 11 am to 12 midday at Birmingham Children's Hospital. Midlands MPs will meet children from the region with PKU and the clinicians that care for them. Contact in advance for media access.

Related Sectors:

Charities & non-profits :: Children & Teenagers :: Government :: Health ::

Related Keywords:

PKU :: Phenylketonuria :: Kuvan :: Birmingham :: Dudley :: Halesowen ::

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