NHS will fund drug treatment for rare condition

Friday 29 September, 2017

A young boy with the rare disease phenylketonuria (PKU) is to commence treatment with the drug Kuvan, after the NHS has conceded that it should fund the treatment. This good news follows a lengthy legal battle in which the child's parents brought a judicial review against the NHS' refusal to pay for the drug treatment recommended by his hospital clinician. The drug is widely used in other countries.

On 8th August 2017 the High Court ruled that NHS England's decision to refuse to fund Kuvan treatment for the child was irrational. Mrs Justice Andrews said that the evidence that Kuvan is clinically effective is "overwhelming". The Court ordered the NHS to reconsider funding Kuvan. On 28 September NHS England confirmed that it would fund the drug treatment.

The child is subject to an anonymity order and is referred to as Child SB. SB is 7 years old and has the rare disease PKU which means he is unable to metabolise phenylalanine, an amino acid contained within protein. If left untreated, phenylalanine accumulates in the brain causing profound and irreversible intellectual disabilities. In the UK, the only available treatment for PKU is dietary management, which involves removing almost all natural protein from the diet to keep phenylalanine levels within safe levels. SB also has autism which has affected his ability to tolerate the very low protein diet and amino acid supplements which are required as part of the dietary management of PKU.

Eric Lange, the Chairman of the national patient charity NSPKU said, "I am relieved that the NHS has conceded that it should provide Kuvan treatment for this young boy with PKU. His family should never have been made to fight the NHS through the courts to obtain a treatment to keep their child safe. Kuvan is an established treatment widely used around the world and it is time that the NHS provided it for other patients in the UK."

Notes for editors:

Phenylketonuria (PKU) is a metabolic disorder. About 6,500 people in the UK have PKU.

Kuvan (BH4) is the only licensed drug treatment for PKU, licensed in the EU since 2008. It is widely used across the world and is reimbursed by most European health systems.

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