

High Court rules that NHS acted irrationally in refusing life changing drug Kuvan to child with rare disease PKU

Tuesday 8 August, 2017

The family of a young boy with the rare disease phenylketonuria (PKU) have won an important High Court victory against the NHS in their ongoing battle to obtain the drug BH4 (Kuvan) to treat his condition.

The child is subject to an anonymity order and is referred to as Child S. S 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.

S 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. Child S's Consultant recommended the use of the drug treatment BH4 (Kuvan) which would lower his phenylalanine levels and prevent the risk of damage to his brain. Kuvan has been licensed in the EU since 2008 and is routinely prescribed to people with PKU across the EU.

The NHS refused to provide the drug despite the known risk that high phenylalanine levels could be toxic to the S's brain without successful management through a low protein diet. The child's family obtained legal aid and commenced judicial review proceedings in October 2016.

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 has now ordered the NHS to reconsider funding Kuvan for the child.

Eric Lange, the Chairman of the NSPKU said, "The family of this little boy with PKU have shown great determination and bravery in fighting the NHS. I hope the NHS will now provide Kuvan treatment for their son swiftly following the Court's judgment. The NHS now needs to ask itself why British children with PKU are denied Kuvan treatment in the light of the Court's determination that there is overwhelming evidence of its clinical effectiveness. Kuvan is already widely used across Europe. We would like to invite the NHS to actively engage with people living with PKU and ensure their needs are met. It should not need litigation to make the NHS listen to us."

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