BioMarin must prioritise the welfare of patients

Tuesday 16 April, 2019

On 16 April 2019 the BBC broadcast an investigation into certain aspects of BioMarin Pharmaceutical's behaviour in relation to the licensing and commercial exploitation of BH4 (Trademark Kuvan) as a treatment for PKU.

The National Society for Phenylketonuria (NSPKU) is the national charity for people living with the rare disease phenylketonuria (PKU). NSPKU supports the use of all safe and effective treatments to allow people with PKU to manage their condition. Kuvan has been a licensed drug since 2008 and the NHS has accepted that there is good evidence to support its use as a treatment for patients. It is a source of great concern to the patient community that this life changing treatment has never been routinely available in the UK. Kuvan is currently being considered for use in the NHS in ongoing healthcare technology appraisals.

Eric Lange, Chairman of NSPKU said "The NSPKU campaigns for better treatment and support for people with PKU. In all aspects of our work people with PKU come first. BioMarin also needs to prioritise the interests and welfare of people with PKU. BioMarin must address all the concerns raised by the BBC about post-trial access to treatment to clinical trial participants. BioMarin and the NHS need to work together to ensure fair access to BH4 treatment for all people who could benefit. It is completely unacceptable for patients to live for a decade without access to a treatment that could help them. A solution is long overdue. BioMarin must provide actions and solutions, not empty words."

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PKU :: Phenylketonuria :: KUVAN :: BioMarin :: BBC Newsnight ::

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