RUH

Royal United Hospital Bath NHS
NHS Trust

14th September 2009

Communications Department
Tel: 01225 82 5849/5799/6230/1299

communication@ruh.nhs.uk
www.ruh.nhs.uk

MEDIA RELEASE

International research, by scientists and paediatricians based at the Royal United Hospital Bath, could help thousands of children who suffer from a rare form of epilepsy.

The Bath Unit for Research into Paediatrics (BURP) promotes and advances medical knowledge and research into childhood disease and this latest trial, for which it needs to raise £500,000, is into infantile spasms. As part of that fund-raising, the father of a child who is taking part in the trials is cycling from Lands End to John O’Groats, hoping to raise £10,000.

Killian Hall, who is cycling for his daughter Grace, called in at the RUH on Monday 14 September.

Kilian, says “At 6 months Grace was diagnosed with a very rare condition called West's Syndrome, a serious form of infantile spasms that occurs in about 1 in 5000 births. In 90% of these children the spasms often cause severe mental and physical retardation.”

“Grace has responded well to pioneering treatment as part of a global trial headed by BURP and her future now looks very bright. To support this incredible charity and as way of saying thank you, myself and Grace’s godfather, Steve, are cycling over 1000 miles from Land’s End to John O’Groats.

Professor John Osborne, who founded BURP 23 years ago, says “Grace is a participant in our international trial called ICISS - the International Collaborative Infantile Spasms Study. This study is our second and is already taking place in over 120 hospitals in the UK, New Zealand, Switzerland, and in Australia this month with Germany, Belgium and Denmark hoping to join too. BURP is hoping to raise £500,000 to spend on improving the outlook for children with epilepsy, in particular infants with infantile spasms.”

If Kilian’s team of cyclists is successful, the £10,000 will go towards developing the programme of work on spasms and in particular to look at ways of being certain about the diagnosis, which relies on the EEG or electrical brain waves. As well as patients at the RUH benefiting from this research, all hospitals throughout the South West of England are also involved in the trial.

Children affected with this condition rarely show any symptoms until some weeks after their birth when they can then become severely disabled and many suffer spasms for several weeks before a diagnosis is made. Professor Osborne’s research will give paediatricians and GPs a better understanding this type of epilepsy and it has already shown that the sooner a child is treated once the spasms begin, the better their quality of life.

For more information about Killian Hall and his daughter Grace, you can visit their blog at http://race4grace.wordpress.com/
or to donate online go to: http://www.justgiving.com/kilianandsteve/

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