



INFORMATION FOR PRESS RELEASES

Infantile Spasms

- Infantile spasms, also known as West Syndrome, is a rare type of epilepsy that occurs in young children, usually under one year of age.
- Infantile spasms affect up to 1 in 2500 children.
- About 400 children a year are diagnosed in the UK.
- This is a serious seizure disorder because a child with infantile spasms has a chaotic brainwave pattern that may cause loss of skills and brain damage.
- Infantile spasms can be very difficult to recognise and is often misdiagnosed as colic and reflux, or startle reflex.
- Unless infantile spasms are recognised and treated early, the prognosis for affected children is very poor.

Typical Symptoms

- The typical pattern is a sudden bending forward and stiffening of the body, arms and legs. Sometimes, the arms and legs being flung outwards.
- Typically, each episode lasts just one or two seconds, followed by a pause for a few seconds, then a further spasm - known as a cluster of spasms.
- A child having infantile spasms may just have little head drops that do not appear to be anything serious.

Jenny Rawling, founding member and Trustee of UKIST says

“Unfortunately, infantile spasms usually have a very subtle appearance, so it’s often difficult for parents to notice, and very few GPs will recognise the symptoms. If you suspect a child is having infantile spasms, they need urgent referral to a neurologist - try to capture them on film and go to your nearest children’s A&E department”.

Belen Robbins, Chairman of UKIST says

“UKIST is committed to raising awareness of infantile spasms, supporting parents and carers of children affected by this rare type of epilepsy, and pushing for much needed advancements in clinical research in to this devastating condition. We would like to offer our support to anyone who is concerned that their child may be experiencing infantile spasms”.

The UK Infantile Spasms Trust (UKIST)

Prior to 2016 there was no infantile spasms support network in the UK. A passionate group of like-minded parents with children affected by infantile spasms established UKIST, and the charity was registered in March 2017. The charity aims to improve awareness of the symptoms of infantile spasms amongst the medical profession and the public; provides a vital network of support to parents and carers with children affected by infantile spasms; and supports the advancement of clinical research into infantile spasms. To find out more about the support available through UKIST visit www.ukinfantilespasmstrust.org.

For further information contact ukinfantilespasmstrust@gmail.com.

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