

### The experience of the UK Infantile Spasms Trust

The UK Infantile Spasms Trust (UKIST) is a small registered charity established in 2017 to support the families of children diagnosed with infantile spasms. The charity was set up by a group of eight families in response to our experiences of a lack of suitable support when our own children were diagnosed.

Infantile spasms is a rare form of epilepsy with an incidence of around 2-3 cases per 10,000 live births, which gives

an estimated 135-200 new cases a year in the UK based on ONS birth rate data for 2017. Most affected families will never have heard of infantile spasms before diagnosis and will have nobody within their existing support network with any understanding of the condition. Since the prognosis particularly in terms of developmental outcomes and developing uncontrolled epilepsy is poor, many parents experience the diagnosis as being a devastating blow.



### UKIST can help by providing...



#### Support and advice

- Psychosocial support and information in our online support group, now numbering nearly 1000 members. This group consists of newly diagnosed families, those with toddlers or children previously diagnosed with infantile spasms and a few older individuals who had infantile spasms in the years well before the charity was set up.
- Opportunities to meet other affected families face to face at our annual fun days and at smaller informal gatherings.
- Advice to parents who are concerned about suspicious movements in their infant.



#### Training and financial support

- Small grants for equipment or therapy to our member families.
- Financial contributions towards epilepsy research.
- Training sessions for primary healthcare staff.



#### Public awareness

- Broader public awareness of the condition through campaigns during infantile spasms awareness week and through our awareness videos.
- Keeping our community updated with the latest epilepsy research findings.
- Building connections with the international infantile spasms and epilepsy groups through membership of the Infantile Spasms Awareness Network.



#### Accurate and accessible information

- An informative website.
- New written materials for recently diagnosed families, developed in partnership with our medical advisor Dr Lux.
- A chapter on the perspective of parents/carers in a proposed new textbook on infantile spasms.



### Making connections

Families who are supported by UKIST feel connected to others with whom they can identify, can have their questions answered, feel less isolated and more optimistic, and can move towards active acceptance of their child's diagnosis. More established members are empowered to help others and the experience of being able to altruistically

support more recently diagnosed families has been shown to enhance their self-esteem and self-worth.

UKIST is keen to work alongside providers of paediatric epilepsy services and other parent/carer organisations to improve the quality of care for paediatric epilepsy patients and their families.

