



**UKIST**  
THE UK INFANTILE SPASMS TRUST

Dear Supporters, Partners, and Friends,  
As UKIST arrives at our eighth birthday we'd like to reflect on the year 2024-25.



### Mission and Vision:

Our mission remains steadfast: to improve the lives of children and families affected by infantile spasms through education, support, and research. This year, we continued to work tirelessly towards building a community that understands, supports, and empowers those affected by this rare and challenging condition.



### Support Programs:

We continue our core work in the UKIST online support group to help families going through the process of diagnosis, treatment and recovery. The charity have provided over £10k during this year in grants to individuals to help with the cost of therapy or equipment to aid their children's development. We continue to offer online speech therapy to all members of the support group through our partnership with Can-Do speech therapy. Chloe has hosted a very popular fortnightly live chat and our group members share their children's progress through monthly warrior stories, weekly Friday photobomb and inchstone posts. We have continued to build a library of information and resources in our 'guides' section and on our YouTube channel.



We now have two annual fixtures for family take-overs at Camp Mohawk in June and the Children's Farm Adventure Trust in September and it's been great to see some of the same families returning each year and watch their children grow. UKIST also offer funding for smaller local meet ups and are keen to encourage smaller groups of families to get together.

**STOP**  
INFANTILE SPASMS

Every day you delay increases your child's risk for brain damage

- SEE THE SIGNS**  
Clusters of sudden, repeated, uncontrolled movements like head bobs or body crumpling
- TAKE A VIDEO**  
Record the symptoms and talk to your doctor immediately
- OBTAIN DIAGNOSIS**  
Confirm an irregular brain wave pattern with an EEG test
- PRIORITIZE TREATMENT**  
End spasms to minimize developmental delays

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## Research and Innovation:

We were proud and delighted to be able to make a £10k contribution to the BEE study, based at King's College London. BEE (brain development in early epilepsy) follows children with early onset epilepsy from about 10 months old, through their first few



years, to track their development and is hoping to identify early markers for some of the developmental conditions that can be a consequence of infantile spasms. UKIST have also supported the study by helping to recruit newly diagnosed families. We also contributed to the preliminary work by Prof Jay Shetty and Prof Sameer Zuberi on two projects based in Scotland - a pilot to evaluate the

effectiveness of a remotely monitored bluetooth EEG cap and a large scale project to develop AI powered analysis of seizure videos submitted on the V-create video platform. These projects each have huge potential to remove some of the barriers to rapid diagnosis. UKIST has committed to part funding the AI video project during our next financial year. Preliminary data from both projects was presented at BPNA conference in Oxford in January 2025.



## Medical Education:

Behind the scenes, the team continue to work with OCB on producing our medical education module which will be hosted on the NHS e-learning for health platform. We will be increasing our attendance at medical conferences over the coming year in order to launch and promote the module, with representation planned at BPNA, RCGP and RCPCH conferences. The links forged with other small charities, epilepsy nurses and neurologists at these events are invaluable.



## Fundraising Success:

We would like to say an enormous thank you to all the wonderful individuals who have fundraised for us over the last year. A special mention has to go to our trustee, Alice, who ran a half marathon every month in 2024 in order to raise money.

Inspired partly by her efforts, Amy and a small team of UKIST runners will compete in the London Landmarks Half Marathon in April 2025. We'd also like to gratefully acknowledge a HUGE donation of **£20,000** from the Phillips 2012 Charitable Trust which is ringfenced for research efforts.



## Collaboration and Partnerships:

As a small charity our reach and impact is enhanced by collaborating with others – we are proud members of the Infantile Spasms Action Network and their annual awareness week in December, the new umbrella charity UK RET (rare epilepsies together) and the European group for Complex and Rare Epilepsies. We also work alongside PADS (positive about Down Syndrome) and MedCan support.

Please scan or search 'UKIST Infantile Spasms Awareness Video' on YouTube.

UKIST  
Awareness  
Video



## Looking Ahead:

The charity has a well established trustee team of ten IS parents and we are now in a good position to consolidate our existing services and extend our reach. Susan Blackburn, our treasurer, has brought her extensive charity experience to bear on improving our procedures and preparing the charity for the next level. We are in the planning stages of providing mental health and wellbeing support for our families via the support group as well as increasing the support available via the grant scheme.

None of this would be possible without our incredible volunteer team and the fabulous fundraisers that make it all financially possible. UKIST remains entirely volunteer led. Enormous thanks to trustees Jenny, Susan, Amy, Michelle, Samia, Louisa, Alice, Kelly, Louise, Chloe and our support group admin team Lynn, Mechelle, Emmi and Kamala.

Here's looking forward to next year!

The UKIST team.



Find us at:

[www.ukinfantilespasmstrust.org](http://www.ukinfantilespasmstrust.org)



UKIST



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