



UKIST

THE UK INFANTILE SPASMS TRUST



Dear Supporters, Partners, and Friends,
As UKIST celebrates its ninth birthday, we are proud to reflect on everything achieved during 2025-26 and to share our plans for the year ahead.



Support for families:

UKIST exists to improve the lives of children and families affected by infantile spasms (IS), and our online support group remains at the heart of that mission. Our families continue to offer one another extraordinary compassion, solidarity and strength while navigating an incredibly challenging journey together.



This year, we were delighted to support several large-scale family meet-ups, including gatherings at **Camp Mohawk**, **Creative Space Centre**, and **The Children's Farm Adventure Trust**. It is wonderful to see families returning year after year - watching children grow, friendships deepen and new connections form.

Our grants programme has continued to expand, with £20,000 allocated this year to fund therapies and specialist equipment. These grants enable access to vital services such as physiotherapy, speech and language therapy, and educational psychology, as well as essential equipment that makes daily life safer and more manageable – including safe space beds and GoTo seats.

We have continued our partnership with Joanne Jones of CanDo Speech Therapy to provide online speech and language support. Early speech therapy is particularly important for children with IS, yet NHS services can be difficult to access before the age of two.



We have also funded Makaton taster and Level 1 courses, delivered by tutor Jacqui Lewis, empowering families with practical communication tools.

Thanks to a generous grant from the Spectris Foundation, we have expanded our mental health support for parents. In partnership with Joanne Sims Wellbeing and Carol and Claire-Louise from the Mindful Parenting Community Project, we now offer online wellbeing sessions and resources tailored to the unique pressures of parenting a child with complex medical needs.

WE HAVE EXCITING NEWS!

WORLD MENTAL HEALTH DAY
19 OCT

Emotional Wellbeing Partnership

with Joanne Sims

ukinfantilespasmstrust

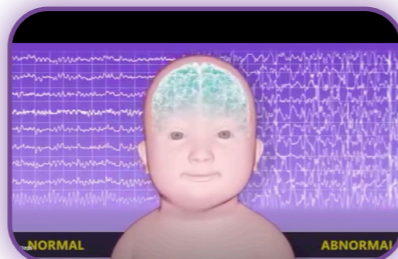
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Medical Education:

A major milestone this year was the launch of our medical education module at the Royal College of General Practitioners conference in Cardiff in October 2025. Developed in collaboration with OCB Media, this project has been a true labour of love over the past two years.

The module is now hosted on NHS e-Learning for Healthcare, representing a significant step forward in our mission to promote early recognition and prompt treatment of infantile spasms.



Over the coming year, we will focus on raising awareness of the module. We have already presented at the British Paediatric Neurology Association conference in Glasgow (January 2026) and plan to attend the Royal College of Paediatrics and Child Health conference in Birmingham (May 2026), as well as returning to the RCGP conference in Glasgow in September. These events have led to invitations to present the module to regional special interest groups, further extending its reach among healthcare professionals.



We continue to collaborate with the Infantile Spasms Action Network (ISAN) and to participate in their annual awareness week each December. This year, thanks to generous sponsorship covering travel costs, Louise attended ISAN's annual meeting in Washington, strengthening our partnerships with colleagues in the United States.



Research:

UKIST remains committed to supporting high-quality research that improves outcomes for children with early epilepsy.

We continue to fund the BEE (Brain Development in Early Epilepsy) study at King's College London, which explores early development in infants diagnosed with infantile spasms or focal epilepsy during their first year of life. The study has now been extended to follow children into their preschool years, and UKIST has committed a further £20,000 for the next financial year. Several UKIST families have participated, and we are confident this research will provide invaluable insights into developmental trajectories and inform earlier, more targeted interventions.



We have also supported the EPIC project at University of Edinburgh, which aims to enable earlier and more equitable diagnosis of epilepsy in community settings through the development of a remote EEG monitoring tool.



Looking Ahead:

None of this work would be possible without our incredible fundraisers, donors and volunteers. Your generosity, energy and commitment make a tangible difference to families across the UK.

Thank you for standing with us - and with our remarkable IS warrior children - as we continue this vital work into our tenth year.

Here's looking forward to next year!

The UKIST team.



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

UKIST Awareness Video



Find us at:

www.ukinfantilespasmtrust.org



UKIST



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