



Dear Supporters, Partners, and Friends,

We are thrilled to share with you the impact made by the UK Infantile Spasms Trust in the past year. Your unwavering support has been the driving force behind our success, and we are excited to highlight the positive impact we've had on the lives of families affected by infantile spasms.

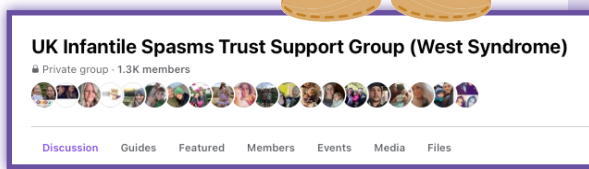
 **Mission and Vision:**

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:**

Our support programs have continued to provide a lifeline for families dealing with the emotional and practical aspects of infantile spasms. In our online support group we have created a network where individuals can share experiences, find solace, and access the support they need to navigate the complexities of this condition. We continue to provide access to online speech therapy and Makaton training for our families, and have built our library of video resources on YouTube. We were delighted to be able to host two large family fun days at Camp Mohawk and CAFT to allow families to meet each other in person and we plan to fund these 'takeover' days again in 2024. We have allocated £10,000 in grant funding to provide equipment, therapy sessions and alleviate hardship for some of our families. Amy Dowding and Susan Blackburn, two members of our trustee team have been collaborating with Fraser Nash to work on a project to reverse engineer or innovate a supportive seat for toddlers, similar to the now discontinued Cushi Tush which our families have found very helpful. We have arranged training to improve our safeguarding procedures and to train and equip the wonderful volunteer team who offer timely advice to worried parents.



Research and Innovation:



In collaboration with leading medical professionals and researchers, we have continued to look for opportunities to invest in groundbreaking research aimed at advancing the understanding and treatment of infantile spasms. We are a partner in research led by Dr Jay Shetty at The University of Edinburgh to use Bluetooth technology to develop remote methods of monitoring EEG, and with the BEE project (brain development in early epilepsy) based in London, which is monitoring the development of children with epilepsy in their first year to better understand how this affects their outcomes. Significant donations to both projects are in the pipeline. We'd particularly like to thank our families who have been willing participants in the BEE project with their children.



Fundraising Success:

We are delighted to welcome Kelly Skinner as a new trustee having been involved in the team as our fundraising lead over the last six months. Kelly organised a very successful UKIST virtual running event in the lead up to ISAW and has initiated a partnership with Twisted Running who now provide our branded sportswear. We're continually humbled by our imaginative fundraisers – not only walking and running for us but also hosting music events and a skydive. Enormous thanks are due to Michelle Scoffield who has been our treasurer for the past five years and is now handing the reins to Susan, but remains as a trustee and lends us her vision and direction for our future growth.

Collaborations and Partnerships:

We are proud to have strengthened existing partnerships and formed new collaborations with organisations that share our vision. By working together, we amplify our impact and create a united front against infantile spasms. We are a founder member of the new charity partnership organisation UKRET (rare epilepsies together) which allows small rare epilepsy charities to expand our reach and work together on joint projects. We continue to work with PADS (Positive about Down Syndrome) to improve early detection in this group of children at increased risk of developing IS, the ISAN (infantile spasms action network) and EpiCare.



Education and Awareness:

In the past year, we expanded our educational outreach initiatives, reaching more parents, caregivers, and healthcare professionals. The return of in person medical conferences meant we were able to have a presence at the British Paediatric Neurology Association conference and the Rare Epilepsy Conference to continue to forge links with neurologists, paediatricians and epilepsy nurses. We are in the final stages of developing our own online

training package for the medical profession, led by Dr Louisa Freer in collaboration with OCB.

We'd like to thank our trustee Dr Alice Goldhill for her contribution to developing material on infantile spasms for the medical education site 'Don't Forget The Bubbles'. As proud members of ISAN (the infantile spasms action network) we took part in infantile spasms awareness week in December to raise awareness of the signs of infantile spasms and the need for urgency in seeking treatment. Our chair Jenny Rawling has worked with EpiCare (the European reference network for rare epilepsy) to produce a patient journey and FAQ document for infantile spasms. We have continued to distribute our children's book 'Bryn Bear's Guide to infantile spasms' to epilepsy nurses and to families. We're grateful to our social media team Samia Sanders and Chloe Cox for their work in keeping our followers informed on what we are doing and to Louise Derbyshire for her work on eye catching graphics.



Don't Forget The Bubbles



Looking Ahead:

As we reflect on the past year, we are energised and optimistic about the future. The road ahead may present challenges, but with your continued support, we are confident in our ability to make a lasting difference in the lives of those affected by infantile spasms. Our major focus for the next year will be to launch our medical education package with increased attendance at conferences and engagement with the medical profession. We are ready to take the next steps to formalise our procedures in order to become eligible for grant funding and we are grateful to Susan Blackburn whose years of experience in the charity sector are helping us achieve this next step.





Thank You:

To our dedicated supporters, volunteers, partners, and the entire UK Infantile Spasms Trust community, we extend our deepest gratitude. Your commitment and passion inspire us every day, and together, we are making significant strides in the fight against infantile spasms.

Warm regards,

Jenny, Samia, Michelle, Louisa, Alice, Amy, Louise, Kelly, Susan and Chloe

The Trustee Team.



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

**UKIST
Awareness
Video**



Find us at:
www.ukinfantilespasmstrust.org

