



## UKIST AGM REPORT

### SUNDAY 25 APRIL, VIA ZOOM

**Trustee attendees:** Alice Goldhill, Belen Robbins (Chair), Jenny Rawling, Louisa Freer, Michelle Scoffield (Treasurer), and Samia Sanders.

**Guests:** Adrian Hutchings, Amy Dowding, Dr Anne-Marie Guy, Dr Charles Steward, Dr Colin Dunkley and Sophie Bristol.

#### 1. UKIST Ambitions

Trustees unanimously agreed to maintain the current charity ambitions, with no amendments:

- **Educate** - to improve awareness of the symptoms of infantile spasms amongst the medical profession and the public (because early diagnosis is key);
- **Support** - to provide a vital network of support to parents and carers with children affected by infantile spasms; and
- **Research** - to support the advancement of clinical research into infantile spasms

#### 2. Family support

**2020-2021 reflections:** despite the global pandemic, UKIST has continued to provide a vital network of support to parents / carers with children affected by infantile spasms. We're particularly proud of:

- The ongoing support offered to newly diagnosed families through our Facebook group.
- Provision of essential virtual therapies during Covid lockdown - including physio, occupational therapy, speech therapy, Makaton, music therapy, and support for emotional wellbeing.
- The launch of our first book "Bryn Bear's Guide to Infantile Spasms" - available globally on a free to download basis. Hard copies of the book coming soon!
- Ongoing award of UKIST Grants for special needs equipment, therapy and activities that will assist children in their recovery or development.

**Support group:** with c.1600 members, we continue to monitor the size of the group to make sure people feel able to share thoughts and concerns in a safe environment. Trustees and lead Regional Parent Ambassadors (RPAs) recognise the value of having a diverse group, particularly at different points in their IS journey. Our primary focus remains on helping families to get a prompt IS diagnosis and treatment with front line medication.

**Grants:** our UKIST grant scheme is made possible by the generosity of our fundraisers and kind donors; and we thank them for making such a positive difference to the lives of children and families affected by infantile spasms. UKIST grants can be used to contribute towards special needs equipment, or therapy and activities that will assist children in their recovery or development. Trustees agreed to align value of grants to a maximum value of £1000 for both therapy *and* equipment with immediate effect. Families are invited to apply in writing with an explanation of the proposed costs and benefits. Applications for UKIST grants are reviewed by the Board of Trustees on a monthly basis.

**Regional Parent Ambassadors & Volunteers:** Covid has prevented many activities from taking place. However, we have a reinvigorated map of members, RPAs and IS aware hospitals. We're extremely grateful to all our volunteers - Trustees, Regional Parent Ambassadors, and for everyone who continues to offer their professional experience to help steer and deliver our ambitions.



### 3. Education

**Progress to date:** in collaboration with our friends at Young Epilepsy and the Infantile Spasms Awareness Network we've created and launched childhood epilepsy and infantile spasms modules on the Royal College of General Practitioners online learning platform - this can be accessed by 110,000 medical staff as part of their ongoing training. We're also working with Red Whale GP Updates, live in Summer 2021.

**Looking ahead:** Trustees have identified a number opportunities for the year ahead, with a particular focus on collaboration with medical professionals. This is likely to include:

- Additional support and guidance for families *and* medical professionals in pre-diagnosis stage.
- Lobbying for video application technology.
- Recommendations for sensitively managing IS diagnosis / outcome conversations.
- Stronger collaboration with other charity support groups and at key points of diagnosis (e.g. neo natal units, down syndrome, brain injuries, tuberous sclerosis).
- Stakeholder review of NICE guidelines.

### 4. Research

No immediate opportunities to support research in to infantile spasms specifically. We remain close to the findings of the International Collaborative Infantile Spasms Study (ICISS) and eagerly await their next report. With increasing scale, we will also actively explore the opportunity to undertake research within our own UKIST community.

### 5. Finances and budget

**2020-21 financial year:** despite the Covid19 pandemic, income was in line with previous year. Of particular note:

- Significant fundraising efforts, largely hosted through our preferred platform (Virgin Money Giving) - thanks to all our fundraisers who never cease to amaze us with their challenges!
- Two grants awarded to UKIST - thanks to Coronavirus Community Support Fund (distributed by The National Lottery Community Fund) and sponsorship from the Child Neurology Foundation.

**2021-2022 financial year:** Trustees have committed to year-on-year increases in budget allocation for:

- Primary healthcare education
- Family support - including grants, regional networking and zoom sessions
- UKIST donations to research
- Merchandise
- Conferences, trustee learning and development
- Charity management - admin, website, insurance, accountancy, and expenses

Funds are to be held in reserve to ensure essential "run" costs can be covered for at least four years.

### 6. Charity Management

**Trustees:** the Trustees agreed to strengthen the team to a maximum of 10 over the coming year, with a focus on increasing diversity of thought and experience - to include additional skills in research, marketing and fundraising, and complex IS / development needs. We would love to hear from anyone who's interested in getting involved - [ukinfantilespasmstrust@gmail.com](mailto:ukinfantilespasmstrust@gmail.com).

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