

Report from UKIST Annual General Meeting (AGM) Saturday 4th May 2019

Attendees – Amy Melillo, Jenny Rawling, Belen Robbins, Samia Sanders, Lisa Martin, Clare Garvey, Michelle Scoffield

Annual Budget April 2019-2020

- Trustees agreed spend guidelines by area based on current charity funds
 - Grant Giving – number of cycles throughout year
 - Research in conjunction with Dr Lux recommendation
 - Virgin – Just Giving set up costs
 - Insurance renewal
 - Accountant
 - Printing and costs
 - Search Engine Optimisation to focus on key search words for undiagnosed families
 - Social media amplification around key dates
 - Merchandise design and production
 - Gifts – ad hoc
 - Fun day fund
 - Parent packs

Trustees

- Michelle Scoffield joins us as a Trustee and our new Treasurer, taking over from Amy Melillo's 2 years as Treasurer. Amy continues in her role as charity Trustee. Bex Gray-Burns retires her role as one of the founding Trustees after 2 years.
- Discussion around expanding number of Trustees in future

Regional Parent Ambassadors

- Lisa Martin to head up recruitment and management of the team to build extended network of support

Fun Days 2019

- Camp Mohawk to move to a one day event
- Discussion around how we can have more events in more regions

Fundraising Platform

- Following the announcement of the closure of My Donate – decision was made to move to Virgin Just Giving – element of set up costs but user friendly and superior reporting and service made it the top choice of all looked at.

Grant Scheme

- Announcement to follow with details of how to apply (first cycle announced on Support group)
- Agreed to two x rounds of grant schemes

- Families in need will be able to apply for funds for children impacted by Infantile Spasms
- Cases will be assessed by board of Trustees – plan to offer a more grants to more families this financial year

Research Funding

- Working in conjunction with Dr Lux to identify research opportunities specific to infantile spasms – plan to set aside £10,000

Courses and UKIST representation

- 2 x Trustees to take part in Epilepsy course to expand knowledge base
- Continue to build delivery and network to medical professionals

All other business

- Possibility of equipment lending library
- Merchandise Production and development
- ‘How can you support UKIST’ – framework to be built and published
- Parent packs and how to support newly diagnosed families
- Discussion and actions pending to ensure full spectrum of outcomes that our families experience – re-instate Warrior of the week/month