

*Dear Supporters,*

*The Trustees thought that we would get you up-to-date with all the news from Astro Brain Tumour Fund. We hope that you enjoy the read!*

### **News from the Trustees**

After guiding the charity from small beginnings to making a real difference to the low-grade brain tumour community, Katie Sheen, founder of Astro Brain Tumour Fund, has taken the decision to retire as trustee as a result of other commitments. However we are delighted that she has agreed to remain an advisor of the charity and will be on hand to offer occasional guidance.

*Katie says: "This has been such a tough decision, but after almost 18 years it feels right to hand on the baton to other families with fresh ideas, enthusiasm and energy to take the charity on into the future. I am incredibly grateful to all the fundraisers, supporters, volunteers and trustees who have helped and inspired me: a charity is only as successful as the people who participate in it, and you have been absolutely amazing, together enabling us to achieve important changes for UK low-grade glioma research. You have made my time at Astro Brain Tumour Fund such a pleasure: I can't imagine ever losing touch with the low-grade glioma community and in my new role as Research Manager at Brain Tumour Research, I will continue to work closely with all of my friends and colleagues at Astro Brain Tumour Fund in order to find a cure for this devastating disease."*

Our secretary, Christine Forecast (Katie's mum), has also decided to retire and the present trustees would like to say a grateful thanks to both Katie and Christine for all their hard work over the years – Christine has organised the Norfolk Family Walk for ten years, an event which has become our biggest fundraiser (almost £90,000 raised in total) and is enjoyed by around 400 adults and children every year, most of whom have been touched by brain tumours.

Also leaving the Board of Trustees is Martin Segal, who has been at Katie's side since the first few months' of Astro Brain Tumour Fund being founded back in April 2001. Martin has raised significant funds for the charity over the years, initially in hope and latterly in memory of his brother Raymond and wife Stacey, both lost to low-grade gliomas. We are very grateful to Martin for his support.

We will be delighted to welcome on board, in the near future, Kathleen Ferry and Teresa Jordan as new trustees, who are joining us for this new chapter in the life of the charity - we are ever more determined to make a difference in the low-grade brain tumour community.



## Fundraising

Supporters and Trustees of the charity have been busy fundraising over the last year. Events include a charity football tournament organised by Mark Blatherwick and Mark Shepherd running the Dorney Half Marathon.

The Lerego Family (below) have been especially busy with events including a charity Nail day and Muddy Trail Race, Ross Preschool Playgroup ran a charity shop for a week, thanks to Joyce Thomas.



Vanessa Fewell and team ran the Hever Castle Triathlon for ABTF and Brain Tumour Research. Donations to the charity were received in loving memory of Chloe Smithson and Catherine Blatherwick. King William IV Inn at Sedgeford held a Pie, Pudding Night and raffle. Rod Barrett donned his Astro shirt once again and took part in the Norwich Half Marathon.

ABTF Trustees, with the help of loyal supporters, have also been busy with car boot sales, supermarket collections & bag packing, fundraising day, cream teas, Christmas party, sales of books & veg and a wear a hat event. The Twelfth Norfolk Family Walk was held on 7<sup>th</sup> October 2018 and proved to be, once again, a great occasion with over 350 people taking part.



Events happening soon include a Christmas Party on 15th December, supermarket collection on 21<sup>st</sup> December and a Pie & Pudding Night on 16<sup>th</sup> January.

***Many donations, large and small, have also been received over the last year and the trustees would like to say a huge thank you to everyone who has supported the charity so generously, either by donating, holding fundraising events or supporting the events, also not forgetting organisations who generously sponsor and advertise the Norfolk Family Walk, each year, free of charge.***

## Research:

### University of Plymouth: Low-Grade Brain Tumour Centre of Excellence



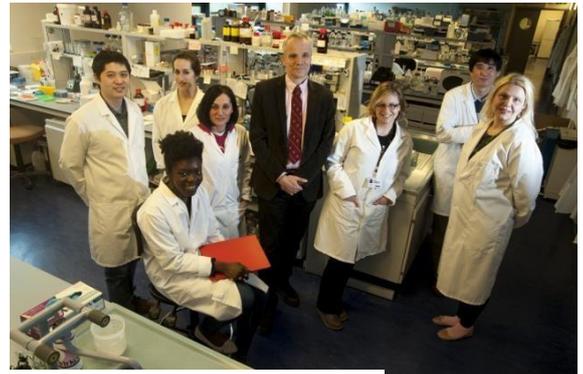
Funded by **Brain Tumour Research**, Professor Oliver Hanemann has built a Centre of Excellence that is now a leading European Research Institute for low-grade brain tumours.

The pioneering research into low-grade tumours taking place at the University of Plymouth includes astrocytoma, oligodendroglioma, schwannoma, meningioma and ependymoma.

Brain tumours are already underfunded, with much of the investment focused on high-grade (fast growing) tumours, yet Professor Oliver Hanemann and his team have taken up the mantle for low-grade brain tumours, **“The Underfunded of the Underfunded”**.

The compassionate, visionary team at Plymouth are determined to change the lives of all those affected by these devastating tumour types.

The Low-Grade Brain Tumour Centre of Excellence consists of a number of teams, all of whom work together in order to share knowledge and progress their discoveries as quickly as possible.



*Professor Hanemann & team at Plymouth*

Astro Brain Tumour fund has made grants to the Plymouth Centre of Excellence totalling £54,800 since 2014 and look forward to donating more funds when they become available.

*As a charity, we actively seek out ways to support research into more gentle, less toxic ways of treating cancer. Whilst finding a cure is obviously our main focus, we also want to ensure that any cure leaves patients with the best possible quality of life afterwards. We also listen carefully to everyone whose lives are touched by brain cancer, and if they are reading anecdotal evidence about treatments on the internet, we encourage research to establish an evidence base for those treatments.*

### Matthew’s Friends and Ketogenic Therapy

We have been co-funding a Dietetics Support Service with the charity Matthew’s Friends since 2014 in order to gather data about the effectiveness of using a ketogenic diet alongside the current standard of care, and that data is now being used to establish the first clinical trial of its type in the UK.

A study carried out by Matthew’s Friends consisting of 25 adult brain tumour patients who chose to participate in a study using ketogenic dietary therapy alongside their standard treatment, saw various benefits including reductions in seizures and improvements in fatigue.

The free ketogenic diet support service for all brain tumour patients is co-funded by Matthew’s Friends and Astro Brain Tumour Fund, with all dietetics support being supplied by Sue Wood and the team at Matthew’s Friends.



## Research to test effect of Cannabidiol on Childhood Brain Tumours

We are also co-funding research into the potential efficacy and safety of cannabis oil for brain tumour patients which will, we hope, start a similar process towards clinical trials. Without a strong evidence base for these new treatments, patients are stumbling in the dark, and as we are named after a star, we hope that our work brings light to that darkness.

This research is being carried out at Nottingham's world-leading Children's Brain Tumour Research Centre, led by Professor Richard Grundy. A non-psychoactive compound found in cannabis called cannabidiol (CBD) is in the process of being tested for its effects on paediatric brain cancer cells.



*Prof Richard Grundy & team*

Professor Richard Grundy said: "Brain tumours are the biggest cancer killer of children in the UK but the disease receives less than 1% of the UK's cancer research funding. New ways to treat childhood brain tumours are urgently needed to extend and improve the quality of life in malignant brain tumour patients so we are excited at the prospect of testing the effect of cannabidiol on brain tumour cells.

"Increasingly families are using CBD, often at great expense, presently there is no evidence that it might be of benefit or even what dose to use or how often. It is therefore very important to obtain objective scientific evidence of whether CBD is active against children's brain tumour cell lines."

### Support:

Our Facebook closed LGG support group, moderated by trustee Linda Rickford, continues to go from strength to strength with over 350 members consisting of LGG patients, their carers and families exchanging valuable information and offering each other support through challenging times on their brain tumour journeys.



### Lobbying

During the last year, trustees of ABTF have been attending the All-Party Parliamentary Group for Brain Tumours meetings at Westminster. The group was established in 2005 to raise awareness of the issues facing the brain tumour community in order to improve research, diagnosis, information, support, treatment and care outcomes.

*We hope that you have enjoyed reading this newsletter and the trustees would once again like to say a very big thank you for all your support in the past year. We look forward to another successful time in the year ahead!*

*With very Best Wishes for a Peaceful Christmas and New Year*

***The Trustees***  
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