

# astro brain tumour fund

Newsletter  
AUTUMN 2014

Funding research,  
offering information,  
inspiration and hope  
for those affected by  
low-grade brain  
tumours

## Welcome to our latest newsletter!

We have been working hard in the last year, raising the profile of low-grade gliomas and fundraising in order to continue to support vital research to discover ever more effective treatments for low-grade brain tumours.

## RESEARCH UPDATE

### Ketogenic Therapy

Astro Brain Tumour Fund is collaborating with Matthew's Friends to offer support and clinical advice to low grade brain tumour patients wishing to try ketogenic therapy.

#### Report from Matthew's Friends:

Ketogenic diet therapy (KD) is based on an individually prescribed low carbohydrate, high fat, adequate protein diet. It was created in the 1920's and is still used in present day paediatric neurology practice, for children whose epilepsy has failed to respond to the best that modern medicine can offer. The outcome can be remarkable! Our clinical experience in the UK has shown us that the KD also works just as well in adults but sadly the ketogenic therapy option is rarely offered, with NHS services limited to one London hospital for the whole of the UK. Hence the work of Matthew's Friends Charity, offering a clinical service to adults and support to adult neurology teams wishing to offer this option to their patients.

It is not just better seizure control adults readily report, but an improvement in associated symptoms such as fatigue,

alertness and overall wellbeing. With these tangible benefits and the emerging research interest in the link between ketogenic therapy and cancer metabolism, it is not surprising that some adults with a low grade brain tumour and life impairing symptoms on a day to day basis wish to trial this option for themselves.



Hence, the collaboration between Matthew's Friends and Astro Brain Tumour Fund.

We are currently supporting nine adults who have been diagnosed with low grade brain tumours (age 28-49yrs), alongside their NHS clinical teams. Six have astrocytomas, two have oligodendrogliomas and one has a medullablastoma. Five are choosing KD due to seizures and associated symptoms while four are adding it to their standard treatment protocol due to tumour progression. Interest in KD as an adjunctive treatment is increasing as neuro-oncology clinicians continue to be frustrated by the limitations of the current therapy on offer. A UK clinical trial is urgently needed and our current work is providing a valuable grounding for this.

### Inside:

*Merlin & Hippo  
Research*  
page 2

*Prof. Denise Sheer*  
page 2



*Fundraising*  
page 3

*Future fundraising*  
page 4



**JustTextGiving**  
by Vodafone

**Text ABTF01 £5  
to 70070**

to donate £5 to  
Astro Brain Tumour Fund  
*Make a difference today*

# Merlin & Hippo Research in Plymouth provides hope for the future

Quite a large group of low grade brain tumours are caused by mutations in the neurofibromatosis type 2 (NF2 or Merlin) gene. These tumours are schwannomas, 30% of all ependymomas and 60% of all meningiomas. The NF2 gene is also affected in some astrocytomas. Currently there is no effective drug treatment that can provide a cure for these tumours, and sometimes the location of them makes surgery and radiosurgery very challenging. Thus, a new therapeutic approach is urgently required for tumours caused by Merlin mutations.

Working in collaboration with a group at the Memorial Sloan-Kettering Institute in New York, the team at Plymouth University Peninsula Schools of Medicine and Dentistry have found a kind of a 'master switch' that accounts for many of the changes in signalling pathways and growth factors occurring in tumour cells with Merlin mutation, and have tested a novel drug that successfully reduces tumour cell proliferation and induces cell death by affecting a core signalling system, the hippo pathway.

**Prof Hanemann says:**

*Dear Astro Brain Tumour Fund staff and supporters*

*This is a big thank you for the support you have given us for our research on low grade brain tumours over the last year. As you know better than anyone low grade brain tumours are the most underfunded and under researched group among the already underfunded brain tumours. This is despite them causing significant suffering in affected patients and their carers. Furthermore research in low grade brain tumours is frequently informative for other brain cancers. So again a big thank you for the support in the last year.*



Astro Brain Tumour Fund will continue their support of Prof. Dr. C. Oliver Hanemann and the Plymouth team as they continue their exciting, groundbreaking work to bring this drug into clinical trials. If you would like to raise money specifically to support this research, please contact us.

## Prof Denise Sheer

**Professor of Human Genetics, Blizard Institute, London**

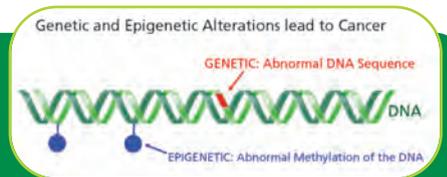
Astro Brain Tumour Fund, in conjunction with Brain Tumour Action, has recently supported Professor Denise Sheer and her team in a detailed study of children's low-grade astrocytomas. Professor Sheer has sent us the following update on the background and progress of the study:

Every normal cell in our body has 46 chromosomes, which are long DNA molecules containing strings of genes. The complement of chromosomes is called the "genome", and as a result of the Human Genome Mapping Project, we now know the complete DNA sequence of the human genome. This is crucial because genes code for all the proteins that keep our cells functioning.

Cancer arises from abnormalities in the DNA sequence (genetic) or in the regulation of the DNA sequence (epigenetic), both of which can make cells divide faster than they should. Therefore, if we can identify genetic or epigenetic changes in the cancer cells, we can begin to understand the cellular processes that give rise to the cancer. Importantly, we can then work to design drugs that specifically target the affected genes and cellular pathways, as a means of controlling the cancer.

In the last few years, we identified critical genetic changes in a large set of well-characterised low-grade astrocytomas in children and shared our findings in several publications. The research funded by Astro Brain Tumour Fund builds on these discoveries, as we are searching for the critical epigenetic changes in the same set of tumours, so that we can gain a truly comprehensive understanding of the molecular basis of cancer formation. Dr. Jennie Jeyapalan, an outstanding senior research scientist in the group, has been leading the programme, working together with other experts in the group and our students.

We have focused mainly on a chemical modification of the DNA, called methylation, which we analysed at over 480,000 sites in each tumour! By comparing the DNA methylation profiles in the tumours with those of normal brain cells, we have made an exciting discovery of a methylation "signature" in pilocytic astrocytomas. This means that these tumours have a distinct pattern of methylation and we find that this correlates with abnormal activity of certain genes. We are currently writing up our findings into a substantial manuscript.



**Denise says:**  
I would like to thank Katie, Mary, Christine, Linda and Martin, and all your wonderful supporters for your interest and generous funding of our research. It would not have been possible to do any of this without you! I greatly enjoyed discussing our findings with Katie Sheer at the British Neuro-Oncology Society meeting in July 2014.

# FUNDRAISING UPDATE

Events that have taken place since our last newsletter include the Seventh **Norfolk Family Walk** at Holkham Hall, Norfolk in October 2013.



*Norfolk Family Walk at Holkham Hall*

Simon Lee, Old Coulsdon Bowling Club, Clare Taylor, Chris Phillips, Kevin Finnerty and Team, John Jennings, Harris & Hoole Coffee Shop, Carol Miller, Alexandre Moate & Hannah, Viki & Chris Callaghan, Natalie Grant, Paul Stephenson, Alexandra Stobbs, Lee Melton, Emma Willsman, Andrew Jordan, Leigh Pearce, colleagues of Laura Smith, Adrian Flux staff, all took part in various challenges and fundraising events in the last year including marathons, half marathons, walks, dress up, dress down and wear a hat days. **Rod Barrett** completed the 2014 Reading Half Marathon and is scheduled for the 2014 Norwich Half Marathon. Rod has now completed 14 half marathons plus the 2011 London Marathon, honouring the memory of his niece, Gemma Barrett.



*Rod Barrett at the Norwich Half Marathon*

**Chris Collings** has climbed Killimanjaro and Ben Nevis, and also helped organise a Charity Football Match, which was supported by comedian John Bishop.

*Chris Collings on Killimanjaro*



**Warrington Borough Council** and **Dunkys Day Nursery** both held Fundraising Days, **Colin & Sue Waller** organised a Supper and Dance, **Viki Callaghan** ran the Running Bears Buff 12 hour Lightning Run, **Chris Callaghan** took part in Rat Race The Wall Ultra Marathon, **Cheryl Myers** ran the Chester Half Marathon, **Vicky Waller** skydived and **James Martin** zip wired over Liverpool. The inspiration for all these fundraisers was brain tumour patient Karan Waller.



*Vicky Waller skydiving*

Other successful fundraising events held in the past year include a Bridge Day, Winter Warmer, Supper & Quiz, Metal Detecting Day, Spring Fashion Event, and Jazz Night. We would like to thank everyone who put so much effort into organising these wonderful events.

Special thanks to Jane and Shirvin who asked their wedding guests to donate to the charity in lieu of presents. Donations were also made to Astro Brain Tumour Fund in loving memory of James Purcell, Trevor Arnold and Rita Gerard.

The Trustees of Astro Brain Tumour Fund would like to thank each and every one of the above mentioned who have helped raise these fantastic amounts. **Big thanks** also to those who have made donations, including valuable standing orders as well as one-off payments.

***Without your support, the research simply would not happen.***

If there is an event or challenge that you would like to arrange or take part in, please contact us and we will help as much as we can.

## SUPPORT UPDATE

Our Patient and Carers Support Groups are going from strength to strength with over 300 members worldwide. The groups are a valuable source of information and support for patients and carers all over the world who help each other through difficult times. All groups can be accessed from our website. We have also opened a "closed Group" Facebook support page for low-grade glioma patients, their families and friends which enables friendly and informal discussion in a private setting.



# NORFOLK FAMILY WALK 2014

Join us at our Annual Norfolk Family Walk for Brain Tumours in the beautiful grounds of Holkham Hall.

The Eighth Norfolk Family Walk, organised by Christine Forecast, Secretary of Astro Brain Tumour Fund, is being held at the Holkham Hall Estate, near Wells-next-the-Sea, North Norfolk, on Sunday, 19th October 2014, from 10am to 4pm.

This popular walk has a choice of distances – one, three, six or ten miles – to suit all ages and abilities. All are through the beautiful parkland, beside the lake and through the woods where deer can be seen grazing. The one mile walk is aimed at children and has games, with prizes, along the way. This walk is suitable for prams and wheelchairs. Dogs on leads are welcome. The ten mile walk also takes in the quaint seaside town of Wells-next-the-Sea where you can stop for a drink or enjoy a lunch of fish and chips on the quayside.

Once the registration fee of £5 has been paid (children free), walkers are then free to support the cancer charity of their choice.

There is also a car park fee of £2.50 which is refundable. There is a café at Holkham Hall where walkers can relax and recover from the walk. The non-walkers in your party will find there is also plenty to amuse them including the House, museum, walled gardens, shop and a free woodland play area.

The Norfolk Family Walk has grown over the years and is one of Astro Brain Tumour Fund's biggest fundraising events.

Participants come back year after year to enjoy walking in the beautiful surroundings of this country estate which is situated on the lovely North Norfolk coast. Some come from different parts of the country and take the opportunity to have a weekend away and enjoy all that this unique area has to offer.

Go to [www.astrofund.org.uk/norfolk-family-walk-2014.php](http://www.astrofund.org.uk/norfolk-family-walk-2014.php) for links to accommodation, sponsorship form, registration form and Just Giving website. Alternatively, contact Christine on 01485 572767 [info@astrofund.org.uk](mailto:info@astrofund.org.uk) or just turn up on the day!

**EIGHTH ANNUAL Norfolk Family Walk**  
at **Holkham Hall**  
for **BRAIN TUMOUR RESEARCH & SUPPORT**

**SUNDAY 19th OCTOBER 2014**  
10am-4pm

Adults : £5 Children : FREE  
Car Parking : £2.50/car  
The walks are: 1, 3, 6, or 10 miles.  
The one mile walk for children has games along the way.  
Prams, trikes, wheelchairs and animals on leads are welcome.

**Brain tumours now account for more deaths among children and those under 40 than any other cancer.**  
Join others and **raise sponsorship** for your chosen brain tumour or cancer charity and **help us all find a cure** for this devastating disease.

The 2014 "World Walk" for Brain Tumours is a project of the International Brain Tumour Alliance (IBTA) and is in its eighth year. We hope to achieve enough mileage world-wide to encircle the Earth at the Equator many times. The "World Walk" symbolically unites all those around the globe whose lives have been touched by a brain tumour.

Go to [www.astrofund.org.uk](http://www.astrofund.org.uk) to download a sponsorship form and for a link to create a justgiving page or contact via email [info@astrofund.org.uk](mailto:info@astrofund.org.uk) or Telephone **01485 572767**

Organised by the Norfolk Branch of Astro Brain Tumour Fund, charity no. 1133561

HOLKHAM IBTA astro brain tumour fund Brain Tumour ADRIAN FLUX

## What will you be wearing on 27th March 2015?



Help us raise awareness and funds by supporting "Wear A Hat Day" in March. Following on from last year's very successful event, there are a variety of ways in which you can help us – by promoting the event, wearing a hat on the day or organising your own get-together.



Help us make **Wear A Hat Day** 27th March 2015 even more successful!



The Trustees of **Astro Brain Tumour Fund** would like to offer their grateful thanks for your continued support

[www.astrofund.org.uk](http://www.astrofund.org.uk)

Registered charity No. 1133561

Christine Forecast, Secretary • [info@astrofund.org.uk](mailto:info@astrofund.org.uk)

Mary Burton, Treasurer • [treasurer@astrofund.org.uk](mailto:treasurer@astrofund.org.uk)

**01485 572767 • 01485 525279**