

ASTRO FUND NEWSLETTER : SPRING 2011

Welcome to our latest newsletter! We have been working hard in the last year, raising the profile of low-grade gliomas on the political agenda and fundraising in order to continue to support that vital research to discover ever more effective treatments for brain tumours.

Research Update

Dr Carol Walker, Astro Fund Brain Tumour Research Co-ordinator, Brain Tumour North West

Brain Tumour North West (BTNW) is an alliance between hospitals and universities across the North West. Since undertaking her new post in September 2010, Carol has played a key role in a number of exciting projects designed to enhance and expand brain tumour research across the region and beyond. For example, she has helped to set up the Liverpool Neuro-Oncology Research Group which brings together researchers and clinicians treating adult and paediatric brain tumour patients in the region, and gained ethics approval to set up a Walton Research Tissue Bank which is now operational. This bank shadows the tissue bank already in place at Preston and works collaboratively to ensure that good clinical cohorts are now available to researchers. This is particularly important for low-grade gliomas which are rare enough to making significant sized studies at a single centre impossible.

Four projects have already been submitted to the Walton Tissue Bank for approval and release of clinical samples and a multidisciplinary, multicentre low-grade glioma study has been proposed which will recruit low-grade glioma patients from Sheffield, Bristol, Liverpool and Preston and will result in molecular, genetic, imaging and blood-borne biomarker research studies being undertaken at the Universities of Central Lancashire, Manchester, Liverpool and Wolverhampton. We look forward to keeping you updated with progress as this groundbreaking new collaborative research gets underway.



Professor Karl Herholz, Professor of Clinical Neuroscience, Director of the Wolfson Molecular Imaging Centre (WMIC), The University of Manchester.

Since Astro Fund began supporting the 'Translocator Protein Expression and Microglial Activation in Glioma' project, the number of glioma patients included in the research has more than tripled. Each has been studied using a PET marker for microglial activation (microglia are the immune cells in the brain). There is a very interesting indication that normal brain, even relatively far away from the tumours, appears to show an increased signal which might be related to the brain's defenses against these tumours. More patients are needed before conclusions can be drawn, so the team will continue working with the neurosurgeons and oncologists for another year.

BNOS

We are delighted to report that our founder, Katie Sheen, has been invited to become a member of the **British Neuro-Oncology Society** and will be attending their conference on 29th June 2011.

Support Update



Our **Patient Support Group** is going from strength to strength and is now nearing 300 members worldwide. Due to its continued success, we have now formed an additional Support Group which is aimed specifically at **Carers**. The group is still in its infancy but already proving to be popular and a valuable source of information and support for carers all over the world who help each other through difficult times. You can access both these groups on our web site.

We are also arranging an **Informal Social Day** for patients, families, carers and our supporters. This will take place on Sunday, 9th October 2011—the day after the Holkham Walk - at a venue in North Norfolk and it is anticipated will include a pub lunch and a chance for people to meet up in a relaxed and informal atmosphere. Please contact info@astrofund.org.uk for more details.

Lobby at House of Commons

Tuesday 22nd March 2011

An unprecedented lobby to MPs was organised by Sue Farrington-Smith for the Brain Tumour Research group of charities, of which Astro Fund is proud to be a member, together with BTUK, SDBTT and IBTA. It was entitled "Don't Forget Brain Tumour Care". Some 200 patients, carers, charities and medical professionals attended and asked MPs to sign up to a brain tumour care charter in support of the Guidance & to make sure the guidelines are not lost in the wider NHS reforms. Details can be found on the BTR website: www.braintumourresearch.org.

Eight Astro Fund supporters—Linda Rickford (leader), Joannie McCutcheon, Andrew Jordan, Amanda Matheson, Duncan Tunstall, Freda Woodcock, Grace Connell and Alison Cook—attended (2 travelled down from Scotland!) and they met up outside the House of Commons. The weather was kind, and all felt it was great to meet other members of Astro Fund and that the event was a powerful message for the powers that be. Many attendees had very positive meetings with their MPs on the day and were personally able to plead for the cause. The tea and cake reception gave everyone an opportunity to mix and mingle with professionals, patients and carers from all over the country, which was a valuable and, at times, moving experience. Their local press were informed of their attendance and some articles were published. For a link to Grace Connell and Linda Rickford's articles in their local newspapers, go to Astro Fund's website. All in all, a great day.



Fundraising update

Events that have taken place since our last newsletter include the fourth **Norfolk Family Walk** at Holkham last October (over £7500 raised for Astro Fund through sponsorships and donations), A "Partylite Candle" party organised by **Linda Rickford** at her home (in excess of £2260) and a "**Winter Warmer**" event at Holme-next-the-Sea (£605).

Alyson Smallwood, who has an astrocytoma brain tumour, wrote a book of poems and proceeds from its sale have topped £1100. Waitrose donated £500 thanks to the efforts of **Linda Rickford** and the third **Bridge Day** at the Old Coach House, Thornham in March amassed £1184. "**Wear a Hat Day**" took place on 25th March and was supported by schools – we await the amounts raised. We have also received generous amounts from collections made in memory of **Gemma Barrett** and **Jean Kent**. **Sara Joyce** ran the Metro Group Marathon, Dusseldorf and raised over £1800.

We have held **collections** at Morrisons and Tesco supermarkets at King's Lynn—proceeds amounting to £578. We attended the Kite Festival at Hunstanton and Tesco Community Fair in King's Lynn and were able to meet many new supporters whilst raising the profile of low-grade gliomas.

Over the year, we have received many donations, including valuable standing orders as well as one-off payments, and we would like to sincerely thank each and every person who has supported Astro Fund in this way. Without you, the research simply would not happen

Some of the planned Future Events

The following are running for the benefit of Astro Fund in the near future:

Stephanie Shinton, pictured right (Birmingham Black Country Half Marathon), **Andrew Jordan** (Honesty Ultra Marathon), **Siobhan Jones** (Llandudno 10 Mile Race). A motorbike rally is planned in Wales and several other events will take place throughout the country—details will be posted on our website as they are confirmed.



A **Grand Draw - "Win a Break in Norfolk"** is being held.

The prizes are **10 Breaks at top North and West Norfolk Hotels**. This will be drawn at the Astro Fund Stand at The Sandringham Flower Show, 5pm, Wednesday, 27th July 2011. Hotels taking part are The Blakeney Hotel, Congham Hall, Crown Hotel (Wells), Heacham Manor, Hoste Arms (Burnham Market), Knights Hill (King's Lynn), Le Strange Arms (Old Hunstanton), Rose & Crown (Snettisham), Titchwell Manor and The White Horse (Brancaster Staithe).

Tickets cost just £1 each and are in books of five

This looks set to be a good fundraiser but your help is needed with buying or selling tickets—perhaps you could take them to work or school, or give friends and family the chance to win one of these amazing prizes?



In conjunction with Macmillan Cancer Support, a **Safari Supper** is being held at Snettisham Park, Norfolk on 22nd June 2011—tickets are £20 each and include a safari to see the deer and their calves, a venison barbeque and jazz. A great summer evening out!



The fifth annual **Norfolk Family Walk** takes place on Saturday, 8th October 2011 at Holkham Hall, Norfolk. There is a £5 entry fee (children free). Car parking at £2.50 is redeemable. As we did last year, any charity associated with brain tumours is welcome to use the walk to raise funds for themselves. Last year over £10,000 was raised by all who took part and 1419 miles were donated to IBTA for their Walk Around the World initiative. Sponsorship, registration forms and posters can be downloaded from our website or we can post one to you. On the following day, 9th October, a social event is planned which will include a pub lunch and give everyone the opportunity to chat in a relaxing atmosphere. More details to follow on our website.

Fundraising Schemes

Thanks to a generous donation, our supporters can now make donations or raise funds by being sponsored at events via **Virgin Money Giving** as well as **Just Giving**. Virgin Money Giving is a non profit—making organisation.



Easy Fundraising is proving an easy and effective way to raise money for free – a total of £300 has been raised to date. Just go to www.easyfundraising.org.uk, select Astro Fund as your chosen charity and do your online shopping as usual.



We now have two new ways to fundraise. We have an "**ebay for charity**" page where items can be sold and the proceeds (or a percentage) are donated to Astro Fund. We have also opened an account with **Recycle4Charity** where supporters can recycle old mobile phones and inkjet cartridges and part of the proceeds go to Astro Fund.

Please go to the "How to Donate" page of our website for direct links to all these fundraising schemes.

We have two pop-up banners with our logo and suitable wording and a small gazebo which anyone is welcome to borrow to help with fundraising.

The Trustees would like to take this opportunity to offer their grateful thanks to you for your continued support

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