



OUR FIRST NEWSLETTER

To All Our Friends:

First of all a huge thank you to everyone who has supported AFRT over the last two and half years. We are all very very grateful and Alison would be immensely proud.

AFRT may have been quiet, but the amount of work that has been going on in the background to establish the Trust has been enormous.

Let us first summarise and recap what the Trust is all about:

We are a registered UK charity, formed solely as a result of Alison's condition specifically for the funding of research, treatment and elimination of a particular brain tumour known as Glioblastoma. Glioblastoma is classified by the World Health Organisation as a Grade IV tumour. There is no worse grading and no known cure. The Trust exists for sufferers, families and all health professionals dedicated to the treatment and care for this form of brain tumour, but recognises that all forms of brain tumour are worthy of further analysis, research and information dissemination. Fund raising will continue in Alison's memory and will be used to help fund a future research project into the causation, nature and treatment of patients with Glioblastoma multiform brain tumours.

Fact:

Did you know that there are at least 19 different types of tumour which affect the brain, and these have 75 sub-types and each of these has many variants. This is therefore a very complex and non-trivial subject and one which needs continual research and investment.

Brain Tumours wait for no one. They control the situation. The need for speed to diagnose and treat the tumour is paramount and the challenge is to achieve this speed against a health system that is not able to travel at the same pace. Our goal is for the Trust to provide help to close this gap.

We are proud of what we have achieved so far, and are immensely grateful to all of our friends for their continued support.

Here are some of our achievements to date:

- We registered the charity with the Charities Commission. This in itself was a significant hurdle and one which put AFRT firmly on the map.
- Trustees, chairman, secretary and treasurer have all been appointed. It is essential that we manage the significant funds that our supporters entrust with us, in a reliable and transparent manner. We firmly believe we have this structure in place.
- With all your help we have now raised in excess of £30,000. Thank you to everyone for all your efforts ranging from a sponsored abseil, a parachute jump to sponsored runs.
- We have sponsored a young resident Neurosurgeon, Dr Nirjhar Hore, to contribute up to date and accurate information to the web-site. He is working closely with the International Neuroscience Institute (INI) in Hannover. Here is their impressive web-site <http://www.ini-hannover.de/>
- Robert and Sue have visited INI in Hannover and have met Professor Samii, one of the worlds leading Neurosurgeons

and Head of the International Neuroscience Institute, a most impressive man.

- We have made an excellent contact with Dr Rita Dobmeyer and her company in Switzerland. Rita knew and loved Alison and has sponsored the Trust and thereby sponsored the work being conducted by Dr Hore in providing technical content.
- We now have three 49 Clubs running and have paid out £1211 in prize money.
- We received official support from the local Council for the 49 Club concept and we can now establish as many 49 Clubs as we like.
- We have held several trustee meetings covering such subjects as the establishment of Trust objectives, Trust logo, fund raising opportunities, considerations of sponsorship and web-site design.
- We have made contact with a number of similar charities and with Sun Microsystems Charitable Foundation and hope to extend this connection over the coming months and years.

And here are some of our deliverables over the coming months:

- We are nearing the completion of our initial attempt at a web-site, which we hope to have up and running by the end of March - more below.
- We are hoping to get another 49 Club up and running in the very near future.
- We are producing our first Newsletter (hope you like it!). We'll try to aim at initially producing two per year, but really the web-site will be the place to gain information about the Trust activities.

- Thanks to much hard work put in by Amber and Damian we have finalised the Trust's new logo and have produced stationary to match.

About the Web-site:

Is it just another web-site? Yes, and we make no apologies for that. Is it accurate? Yes, it needs to be. Is it useful? That is for others to determine, but remember that brain tumours wait for no one. Speed is paramount in diagnosing and treating any form of brain tumour. Therefore having one point of reference in a web-site like this facilitates that speed. During Alison's illness, it was virtually impossible to go to a "one stop shop" to find out more about a condition that none of us had previously heard of. We hope therefore that the web-site in some way overcomes the previous shortfalls encountered and that the single repository of information provides knowledge that all people connected with brain tumours crave for. Look for us at www.afrt.org.uk

We welcome additional content, technical support, funding, applications for research sponsorship and advice in order that we may all improve our global understanding of this tragic condition. We really are dedicated to and passionate about passing on all information concerning Glioblastoma and we are determined to provide as much support as possible to sufferers and their families. Our operating costs are less than one percent of funds raised thanks to the kindness and dedication of so many people.

Finally, we make no bones about it. We need money to help fight this condition! If you can help in anyway please do get in contact with us.

Thank you

Andy Balchin, Robert and Sue Kettlewell, Graham Panton and Roy Death