



Alison Fracella  
research trust



Newsletter May 2014

**TO ALL OUR FRIENDS: THANK YOU SO VERY MUCH!!**

A very warm welcome to our latest newsletter and a huge, huge thank you to everyone who continues to support us.

At the end of April we were able, thanks to your generosity and on behalf of everyone who supports us, to present the Oncology Research Team at the Royal Marsden Hospital with a cheque for an amazing £10,000 !!!



All the money will be directed towards research into glioblastoma and also help to fund a much needed specialist nurse who is working with glioblastoma patients and their families offering informed, practical hands on support where it is much needed. Being able to talk to someone who understands what you are going through when

diagnosed with a brain tumour, has time to listen and, most importantly, someone who knows the nature of the disease can make a world of difference to patients and to their families.

Amanda Heaton the Fundraising Manager at the Royal Marsden says in her letter of thanks

" Dear Sue and Robert,

It was lovely to meet you and the trustees of the Alison Fracella Research Trust and thank you so much for presenting to Frank Saran the most superb donation for the amazing sum of ten thousand pounds. This generous sum will be for the benefit of the Royal Marsden Cancer Charity - Glioblastoma Research Fund.

It is not often that one gesture can affect the lives of so many people, but this donation is a very special gift indeed and we are determined to make it work hard for us. At the Royal Marsden we are dedicated to making life better for people with cancer and keep striving towards a future without it. It is thanks to our wonderful supporters that we are a world leading innovation centre, pioneering new treatments that save lives using our research everyday to provide the very best in diagnosis, treatment and care."

### **Progress report from Dr Frank Saran, Consultant Clinical Oncologist and Head of Neuro-Oncology at The Royal Marsden Hospital**

The Neuro Oncology Research Department at the Royal Marsden are very grateful to have the continued support of the Alison Fracella Research Trust. Over the past number of years, the Trust has helped to fund a dedicated neuro-oncology research fellow and has supported our participation in national and international clinical trials. We are delighted to have the opportunity update the Trust on recent progress.

The neuro-oncology unit is still privileged to be able to offer the largest clinical trials portfolio for patients with primary CNS tumours in the UK. One of the recently completed studies in the first line treatment of glioblastoma was the AVAGlio study. This was the largest international, multicentre study in patients with glioblastoma. It investigated the role of bevacizumab, a drug that targets blood vessels. The Royal Marsden was one of the highest recruiters to the study, with your support. The results of this study were presented at the American Society of Clinical Annual Meeting in Chicago in June 2013. Since then, the study has been published in a leading medical journal, the New England Journal of Medicine. Dr Saran, as part of the steering committee, was one of the authors of the publication (Chinot, Wick et al. 2014).

In July 2013, our new research fellow Dr Alken joined the unit. This is the third research fellow we have had substantially supported by the AFRT. The main role of the research fellow is to increase the recruitment of patients with brain tumours, including glioblastomas, to clinical trials as well as provide high quality personal support both medically and emotionally to these patients. This has coincided with

the opening of two new late phase clinical trials for newly diagnosed patients with glioblastoma. These studies ask two distinct questions: the first is a trial of a targeted vaccine treatment and the second is follow-on study of bevacizumab in glioblastoma. With the new research fellow and new trials, we have increased our enrolment into clinical trials, increasing the options for patients effected by these rare and difficult to treat malignancies. Knowing the importance of translational research (research which uses information from patients and tumours to develop treatments), we continue to participate in the National Brain Tumour Study.

The options for patients with recurrent glioblastoma are few. At the Royal Marsden we are lucky to have access to phase I trials, through the Drug Development Unit. Over the past year, we have increased the number of patients who are offered these experimental drugs, an opportunity that patients would otherwise not have. Indeed, our work on this will be presented at the American Society of Clinical Oncology Annual Meeting this year in Chicago by our clinical research fellow. We continue to collaborate with colleagues across the UK and beyond to discover the next treatment paradigm for glioblastoma. Since our last update, we have two more experimental drugs which are being trialled in patients with glioblastoma.

We are very glad to have the opportunity to participate in The National Brain Tumour Study. We work very closely with our colleagues in the Institute of Cancer Research on this project and recently we have collaborated to increase the number of patients who can participated in this study. Studies such as the National Brain Tumour Study are vital for ongoing advancement in treatment options for patients with primary CNS tumours. They allow us to identify new targets for treatment of these tumours.

Over the next year, we aim to increase the options for our patients by increasing the number of trials available. We continue to work with colleagues in the Institute of Cancer Research to identify potential targets for treatment. The work of the Alison Fracella Research Trust continues to be an essential support to the department as unfortunately the cost associated with clinical research are only marginally met by the current NHS funding.

Chinot, O. L., et al. (2014). "Bevacizumab plus Radiotherapy–Temozolomide for Newly Diagnosed Glioblastoma." New England Journal of Medicine **370**(8): 709-722.

## FUND RAISING

### KERN and JAMES' CYCLE RIDE

(from right to left) Kern Death, Mark Oxford and James Baylham on completion of the London Revolution, an incredible achievement by them all.



Very many congratulations to Kern Death and to James Baylham for cycling in the London Revolution 2014 for Alison's Trust. It was an amazing achievement on the hottest day of the year so far. The London Revolution Cycle Ride took place over two days. The route covered a distance of 190 miles and was an extremely tough challenge, in fact Kern said that it was the hardest thing he had ever done. They did so incredibly well and took it all in their stride, finishing in an excellent time. Our grateful thanks go to them for all they have raised for the Trust.

### 49 CLUB LOTTERY

Our monthly lottery continues to raise a considerable amount for us each year. Thank you very much to everyone who continues to support us through having a ticket (subs due again very soon!) and also to the kind people who have donated their winnings back to the Trust. It would be so good if the numbers that have never ever put in an appearance as the winning bonus ball numbers in the National Lottery every first Saturday of the month would hurry up and do so!



## IPSWICH ROTARY CLUB



Rob and Sue with the President of the Ipswich Rotary Club Bernard Hinds and Vice President Isa Graham

Rob gave a presentation and talk to the Ipswich Rotarians where we were made very welcome at their lunch time meeting on July 25<sup>th</sup> at the Holiday Inn. Rob told them a little of our personal journey and of how the Trust had been formed. He was able to explain the aims of the Trust and we are very grateful to them for allowing us to raise awareness for our cause. There was much interest and we were able to answer questions from the floor. Everyone was very kind and incredibly sympathetic towards our sponsorship of research into glioblastoma at the Royal Marsden. The club later presented us with an incredibly generous donation of £500 for which we are extremely grateful.

### **HADLEIGH MAY SHOW**

We have also been extremely fortunate and sincerely thank Clare Lock, the organiser of last year's Hadleigh Show, for naming us as one of her chosen charities. The show's theme was "families" and she wanted for us to benefit as we are a local, family based charity. She gave us a very generous cheque for £500.

## QUIZ NIGHT



Team Maria and Paul working hard!!

Back by popular demand our joint Quiz Night in November was an amazing success thanks to the hard work of so many people. In fact we couldn't have squeezed any more people into the Ansell Centre!

We had a fantastic turn out with 126 players that was 20 tables! Roy and Rob did fantastically well with our licensed bar being kept very busy all evening and Sue, Amber and Maria did an amazing job with the raffle, they were in fact rushed off their feet! We were so lucky to have been given some fantastic prizes including a sat-nav and DVD player for a car. The prizes were in fact too numerous to mention and we were overwhelmed by the generosity of so many people.



Rae, Richard and Bob enjoy the night!



Some of the many raffle prizes

Everyone told us what a fantastic evening it had been. The ploughman's supper went down very well too!

After all the expenses had been covered we raised an incredible £1,517 which was shared equally between our Trust and the Brendan Oakes Trust.

We have been asked to run another Quiz Night again this year and hope to do so in November, the date will be advertised in the Community News in the Autumn.

## CREAM TEAS IN JUNE

Helen Golland of the award winning teashop Angel Delights in Hadleigh High Street is very generously organising cream teas in the Ansell Centre on Saturday June 21<sup>st</sup> at 3pm for Alison's Trust. Ali loved her cream teas! Homemade cakes will also be on sale. Everyone is very welcome to come and tickets are on sale available from Helen at Angel Delights tel 828191 from Sue Kettlewell 827206 or from Sue Death 823938. A very enjoyable and delicious afternoon is ahead!



Last but by no means least we would like to say a very big thank you for the many donations received from far and wide during the year for which the Trust is extremely grateful. All monies go towards the project we are helping to fund at the Royal Marsden Hospital. Our administration costs are negligible. Let's hope and pray that one day the missing piece of the jigsaw will be found.