

Newsletter May 2016

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 our cause.

Last year we were able to report that, thanks to your generosity and on behalf of everyone who supports us, we were making arrangements to present the Neuro Ongology Research Team at the Royal Marsden Hospital with a cheque for another amazing £10,000.

We made this presentation at the hospital in September!!! Thank you all so very much!!



Amanda Heaton, Sue Kettlewell, Andy Balchin, Frank Saran, Kathy Greenwood, Rob Kettlewell (and special thanks to our trustee and photographer Graham Panton)



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

" Dear Sue and Robert,

It was lovely to see you and the trustees of the Alison Fracella Research Trust. Once again thank you for your tremendous support and in recognition of your marvellous achievement I am delighted to present the Alison Fracella Research Trust with a certificate on behalf of us all at the Royal Marsden.

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."

Dr Niamh Coleman, Clinical Research Fellow in Neuro-Oncology at The Royal Marsden has given us the latest progress report:

Dear Team and supporters,

It is a pleasure to update you on the progress of the Neuro-oncology Research Department in the Royal Marsden. We continue to be very grateful to have the continued support of the Alison Fracella Research Trust. Over the past number of years, the Trust's substantial contributions have helped to fund an interdepartmental neuro-oncology research fellow and have supported our participation in national and international clinical trials. I am the fourth research fellow to have been substantially supported by the AFRT. My main role is to increase the recruitment of patients with brain tumours, including glioblastomas, to clinical trials, by working in tangent with the Drug Development Unit. I also aim to provide high quality personal support both medically and emotionally to these patients.

As you know, the options for patients with newly diagnosed and recurrent high-grade gliomas are limited. However, progress is coming! At the Royal Marsden we are in a unique environment to foster change and have regular access to phase I trials, through the Drug Development Unit and indeed large national and international phase II and III clinical trials through our neuro-oncology unit.

Over the past year, we have been able to offer patients access to several novel experimental drugs, including immune therapies. We have 2 new studies opening in the coming months for patients with newly-diagnosed glioblastoma. One study for example, looks at the addition of nivolumab to standard chemo-radiotherapy for newly-diagnosed patients with glioblastoma. Nivolumab is an exciting immunotherapy agent which has shown promise in many other cancer subtypes (such as lung cancer and skin cancer). It works by blocking a body substance called PD-1. Blocking PD-1 helps the body's immune system to attack cancer cells.

PARADIGM is another trial we are actively recruiting, in collaboration with our colleagues across the UK. PARADIGM is a Cancer Research UK (CRUK) supported study which is looking at olaparib and radiotherapy for elderly people with glioblastoma. This study aims to expand the treatment options for newly diagnosed elderly patients with glioblastoma, whose treatment poses particular difficulties. To date, we have recruited the highest number of patients in the UK to this trial.

We are lucky at the Royal Marsden to have access to novel treatments, and continue to work with our colleagues in the Drug Development Unit, investigating novel therapies in recurrent brain tumours. We are currently participating in a number of early phase clinical trials evaluating novel treatments. For example, in one trial we are investigating a drug called olaparib which is a type of biological therapy called a PARP inhibitor. PARP is an enzyme that helps damaged cells to repair themselves, and if PARP is blocked, cancer cells may not be able to repair themselves after chemotherapy. This could make the chemotherapy work better, and we are currently investigating olaparib with temozolomide chemotherapy. The aim of this trial is to find the best safe dose of olaparib you can have with temozolomide for glioblastoma that has come back, and to learn more about the side effects of taking these 2 drugs together.

With the support of the Trust, we are also continuing to collaborate with our colleagues in St George's Hospital and the Institute of Cancer Research to create a new partnership, which will lead to the formation of a brain tumour tissue bank, a tumour imaging bank as

well as expanding our portfolio to investigate new hypotheses in a preclinical setting. The name of this newly formed group is CENTRANOMIC (Centre for translational neuro-oncology and molecular imaging of cancer). Our aim is to provide the framework for extensive translational research, further allowing the investigation of novel targeted agents for patients with glioblastoma.

As always, the work of the Alison Fracella Research Trust continues to be an essential support to our department and is instrumental to the functioning of our unit, helping us to take preclinical developments to the clinic, and directly benefit patients with malignant brain tumours. Over the next year, we aim to continue to increase the options for our patients, by increasing the number of trials available, and continuing to search for potential new targets for treatment.

Thank you for your continued support.

Fund Raising; Quiz Night!

Once again the Ansell Centre was packed for our annual Quiz Night held on November 28^{th} . A very big thank you to everyone who supported us in so many ways helping to make the occasion so successful and, most importantly, everyone said that the evening was really enjoyable and great fun. The ploughman's supper was again a big hit with everyone too! After expenses, on the night we raised an amazing £1,200 which has been divided between our two charities. Almost every penny raised will go towards the work we are supporting as our charity has minimal administration costs.

Special thanks to Sue and Roy for their valued help and to Maria, Paul and Carol too. A huge thank you to Avis Printers for once again printing our tickets and for selling them for us in the shop. Many thanks also to the people who were so generous in their donations of the many fantastic raffle prizes too numerous to mention. Special thanks though to Mark David for his donation of a full day course at the Cooking Experience, to Hadleigh Tyres for the donation of an MOT and to Kerridges of Needham Market for their donation of a full car valet. Many thanks also to Paul and Marion for their generous prize of a day's sail on the River Deben onboard the splendid catamaran Wakey Wakey. Also to Mandy Painting of the Beauty Gallery at Lavenham for her donation of treatments and products.

Thank you once again to everyone who came and gave us such generous support. It would be fantastic to see you all again this coming November!



Congratulations to the Winning Team

Wool Cottage Raffle



Last Autumn the
Trust was so very
fortunate to have a
wonderful prize of a
short break at Wool
Cottage (part of the
Blaize Barns complex)
in Lavenham donated

to us by Carol Keohan. It was extremely kind and generous of her. The cottage is a 16^{th} century grade 11 listed building with English Tourist Board 5 Star Gold Rating, Trip Advisor 5 Star and 2015 Award for Excellence.

We decided to raffle the break and over the Winter months sold all 250 tickets far and wide including Essex, Sussex, Dorset, the Midlands,

Yorkshire and Wales as well as locally. The tickets were snapped up and at £5 each have raised a staggering £1320 for the Trust (including some very kind donations)

Very many thanks to everyone who had a ticket and to those who sold them for us. It was especially good to be able to reach out to people further afield as well as to our very loyal friends at home.

We asked someone completely independent of the Trust to come along to draw the winning ticket for us on 20th February at a Trustees' meeting. The winning ticket drawn out of the hat was number 203!



The very lucky winner lives in Derbyshire. She and her husband have never visited Suffolk before! They are certainly in for a real treat with so much beautiful countryside and coastline to explore during their 5 day stay at the stunning Wool Cottage next Autumn/Spring at a time of their choosing.

Many congratulations go to our winner and our very grateful thanks to Carol for giving us such a fantastic prize.

Ceilidh and Hog Roast: Happy Birthday Veronica!!



In July a close friend and work colleague of Alison,
Veronica Balchin had her big 60th birthday celebrating in
Dorset with a Ceilidh and Hog
Roast. Veronica used the event to raise money for the Trust.
Her husband Andy is the
Trust's hardworking chairman.
Andy and friends erected a marquee in a field next to their house for the party, it was a great event with dancing into the night.



The men all wore tartan (don't they look splendid in their kilts!) and

the ladies were, traditionally, in white.



The Ceilidh in full swing!



In celebration of her birthday Veronica very kindly asked for donations to the Trust in lieu of birthday presents. Her guests were amazingly generous and the event raised a fantastic £1069. 77p for us (including Gift Aid) Thank you Veronica so very, very much!!

49 Club Lottery

Our monthly lottery continues to raise a considerable amount for us each year and be a valuable source of funding. Thank you so very much to everyone who stays with us and continues to support us through having a ticket (subs due again very soon!) and also to the very kind people who have donated their winnings back to the Trust.

You will all be aware that the numbers in the National Lottery have been extended from 1-49 and are now 1-59!!

We welcome 10 new members and as of July 2016 the Club will become the 59 Club Lottery with the prize each month being £59!

Coffee Morning at Great Bentley

Many thanks to Jane Allison and to all at Great Bentley Methodist Church for very kindly organising a coffee morning for the Trust on the 6th May at their Church. The event was a great success. With home made cakes and produce on sale too. Jane says that there was amazing support from so many people locally and from further afield. Thank you all at Great Bentley so very much.

Future events:

Cream Teas in June

Back by popular demand!! Helen Golland of the award winning tea shop



in Hadleigh High Street Angel Delights is organising another Cream Tea event for us on the afternoon of Sunday June 26th in the Ansell Centre at 2.30pm. Tickets priced at £6 are on sale at Angel Delights or available from Sue Kettlewell phone no 01473 827206 or from Sue Death 01473 823938. It is so kind of Helen to do this for us again and we are all looking forward to sampling her delicious scones laden with her home-made jam and cream!

Very best wishes and many thanks for your continued support from the trustees Andy Balchin, Roy Death, Graham Panton and Sue and Rob Kettlewell