

Newsletter

Issue 2

www.kcsn.org.uk



Welcome to the second edition for 2017

The team at Kidney Cancer Support Network have been very busy since the last newsletter. Training has been taking place at **The Royal Marsden Hospital** in London and at **The Christie Hospital** in Manchester for our **Patient Champion Programme**. KCSN is grateful to patients and carers for taking on these important roles and the medical teams giving their support and assisting in the training.

We are also proud to announce that KCSN will be taking part in first ever **World Kidney Cancer Day** in conjunction with charities, organisations and health professionals all around the world. We would like to invite you to take part with us for this exciting event later in the year. More information is on page 2.

Please look on page 2 about **Cabozantinib** and our request for **urgent help** in getting access to this drug.

The Editorial Team

Patient Champion Programme

KCSN have launched their **Patient Champion Programme**, a patient-led initiative to build awareness of kidney cancer research and clinical trials. The aim is for our members to provide information, support and encouragement to patients taking part in trials and raise the profile of kidney cancer research amongst patients. **KCSN** are very proud that the project is being run in collaboration with the **National Cancer Research Institute (NCRI) Bladder and Renal Cancer Clinical Studies Group**. Patient champions will be trained in clinical trial methodology and the regulations surrounding clinical research through regional training workshops. The first two of which recently took place at **The Royal Marsden** in London and at **The Christie** in Manchester. **Dr James Larkin**, a consultant medical oncologist at The Royal Marsden and KCSN trustee and **Dr Fiona Thistlethwaite**, who is a consultant medical oncologist at The Christie joined **Rose Woodward** of KCSN to host the workshops.

Katie Barrett and **Jeffrey Wynn Davies** each spoke at a workshop about their experiences on a trial. It was very interesting to hear from a patients point of view. Their honesty about taking part and the reassurance of those extra tests, together with the responsibility of being part of a trial, showed the importance of the patient champion role. More details of their talks are on the website and worth a read.

Lynda Pyle and **Susanna Smith** are both specialist renal cancer nurses with many years of experience behind them. They gave an insight into how treatments have changed in the last 10 to 20 years and explained the importance of accurate and relevant information for patients and the important role of managing patient expectations. It was reassuring to hear the amount of support given by the nurses and how enthusiastic they were for this new initiative.

Julia Black, a patient advocate, and **Sharon Kell**, a clinical scientist, introduced the workshop participants to the KCSN website including the Clinical Trials Hub, Trials Database, Information Hub and the Patient Registry. There were useful discussions on how to use the resources and what improvements will be made in the future.

There were also talks by **Maggie Wilcox** (Independent Cancer Patient Voice) about their work, **Dr Natalie Pattison** (National Institute for Health Research and Biomedical Research Centre at The Royal Marsden) who explained funding for research and Clinical Research Networks. **Karen Inns** (Patient and Public Involvement Lead at NIHR) explained the importance of patient involvement in research. They were very interesting talks and discussions and more details are on the website. Rose Woodward along with Dr James Larkin at The Royal Marsden and Dr Fiona Thistlewaite at The Christie explained the purpose of the Clinical Study Group and the role that our new Patient Champions will have to help with pushing research forward.

Everyone who attended the two workshops left feeling enthusiastic about the programme and positive about the work KCSN is doing to get better treatment and support for kidney cancer patients. It was also great to put names to faces and meet fellow patients and carers. There is a lot more information on the programme and the two workshops so please visit the website:

www.kcsn.org.uk/clinical-trials-hub/patient-champion-programme/



Thank You!

To all those who have sent in donations to us in the last month including those who sent in their first new plastic fivers. It is a great idea and it was lovely of you to think of our charity.

We are also grateful to those spending online via easyfundraising (www.easyfundraising.org.uk/causes/kidneycancersupportnetwork) and for the donations via TotalGiving (www.totalgiving.co.uk/charity/kidney-cancer-support-network). Remember when you book your holidays go via the easyfundraising page to get free donation to KCSN.

First Ever World Kidney Cancer Awareness Day

The **International Kidney Cancer Coalition (IKCC)** and its affiliate organisations around the world are launching the first ever **World Kidney Cancer Awareness Day** which will take place later this year. KCSN, a founding member of IKCC, is at the heart of the campaign. Rose Woodward is part of the international steering committee of kidney cancer experts, patients and communications professionals from Singapore to Belgium to Australia exploring how we can raise awareness globally. At the IKCC Expanding Circles conference in Warsaw in April more details of the global campaign will be announced. Kidney cancer is a serious but often forgotten disease and more information about this important awareness campaign will follow in the next few newsletters and on our website from April onwards.

We are planning on having events around the UK and also hoping to have some fundraising activities to help support the work being done by KCSN. Do you want to be involved? We would like our members to hold a pub quiz, coffee morning or tea party etc. to raise the profile of kidney cancer in your local area. If you have any inspirational suggestions please do let us know. The first ever World Kidney Cancer Awareness Day will form part of a week long awareness campaign.

We would also be interested in hearing from anyone who is willing to be interviewed by local or national media to talk about kidney cancer and in particular their own story. We want to make the most of the week and raise awareness of kidney cancer, the need for ongoing research and also highlight all of the support we can offer to patients and their family. So, do keep an eye out for news of all events in our future newsletters. To subscribe to the newsletters or to contact us with offers of help please email us on: team@kcsn.org.uk



URGENT REQUEST FOR HELP: CABOZANTINIB

NICE have refused to approve Cabozantinib for treatment for kidney cancer in England. It is our job as a patient support charity to be the voice for the patients who need access to proven clinically effective drugs. We need that voice to be strong. Are you taking or plan to take Cabozantinib? If you have experience of Cabozantinib please tell us what it means to you to have the drug. Are the side effects manageable? Why do you need access to it? Help us to help you.

Email us by Friday 3rd March on Team@kcsn.org.uk

Charity Wills Month: March 2017

Have you got an up to date will? During March some solicitors and charities have combined forces to encourage everyone over the age of 55 to draw up a will. It is a **free** service and is on a first come first served basis, so click on the link and book your appointment.

<https://freewillsmoth.org.uk/>

Travel Insurance & Access to Treatment

Julia Black has updated the information that has been posted to our website. You will find it in our **Patient to Patient Help Sheets**. So when you book your holiday or have questions about access to a drugs where you live please do check our website for all the latest news and information:

www.kcsn.org.uk/information-hub/patient-to-patient-fact-sheets/

Twibbon



Look out for our brand new Twibbon on Facebook and Twitter. With our motto **Stronger Together** and our name on the ribbon you can add it to your profile picture and help to raise awareness of all the support available to all kidney cancer patients and their families.

Contact details: Kidney Cancer Support Network

Website (including patient forums):
Facebook group:
Twitter:
Email support:
Phone support:

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in a plain text format,
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