

Newsletter

Issue 6

www.kcsn.org.uk



Welcome to the latest edition. We hope you have had a lovely summer. There is a lot of news to share on our new initiatives and some lovely stories from our fundraisers who are enabling us to continue both our new work and to extend our Trials Database. We have news regarding new treatments too. KCSN also want to ask for your input into some research. So please do get in touch with us if you would like to get involved.

Best Wishes

The Editorial Team

Clinical Trial Database

The KCSN Trial Database is continuing to build and has now an impressive list of 40 clinical trials at 200 sites in the UK. Trials are added monthly and are being translated into patient friendly-language so that patients can look through it themselves and then talk to their medical team about options. There is also a list of questions that you can ask your doctor if you are considering taking part in a trial. Its also aimed at doctors looking for alternative options for their patients.

In the last week, studies added included: the investigation into biomarkers for kidney cancer; immunotherapy combinations; inoperable tumour treated with biological therapy together with an immunotherapy; adjuvant treatment with immunotherapy; combination therapy for gastrointestinal and genitourinary tumours; several trials for metastatic solid tumours. More sites for current trials were also added.

It is incredible time for research into kidney cancer and we are working with the medical teams and researchers to make sure the information is accessible. If you are looking for options and need some help then do contact us.

All the information on clinical trials, where to find them, how to access them and what to expect are on the website:

www.kcsn.org.uk/clinical-trials-hub/clinical-trials-information

Cryoablation for Kidney Cancer Tumours

Many of our members have had cryoablation instead of a partial nephrectomy for small tumours, thus preserving more of the kidney and function, and recovered well from the procedure. Studies at the Mayo Clinic compared risks and outcomes and concluded that there was no significant differences and that it should be verified on a large scale trial. We will keep you informed of progress.



Neoadjuvant Treatment

In a study at the Duke Cancer Institute in America, the SURTIME clinical trial compared immediate nephrectomy versus 3 months of Sutent treatment before nephrectomy in people with metastatic kidney cancer at diagnosis. Results show more than doubling the overall survival for those having the drug, then surgery then continuing on Sutent.

More details are available on the website:

www.kcsn.org.uk/news-room/news

FLU JAB

Its that time of year again! It is a good idea for both patient and their carer or other members of their household to have the jab. You can have this whilst on drug treatment but if concerned please do contact your consultant or CNS.

What do you hear when your Doctor tells you news?

We are looking at how patients, and their carers, comprehend what is said in a consultation and how to access your medical records.

Do you comprehend everything that is said or are you still thinking about the first statement and have missed everything else. Are the terms understandable? Have you heard the word cancer and started planning your funeral without hearing about the good treatment options or did you realise that some patients can be treated as a chronic disease not a terminal one? Would you like to have a prompt letter confirming the details and the ability to ask for clarification or would you prefer to wait until the next consultation?

Do you get copies of your scan results and cc'd with letters to your GP, would you rather not know or have you been refused by your consultant?

We are interested to hear your views. If you are willing to help improve the communication between medical staff and patient then please do let us know by sending us an email and we will include you in our survey.

A big **Thank You** to all those who have spent money via easyfundraising to support the work of KCSN. It doesn't cost anything to use, the online retailer pays the donation, so please do visit the website when you buy or book online to support us:

www.easyfundraising.org.uk/causes/kidneycancersupportnetwork

We would also like to thank those who send monthly donations or give via their payroll. These donations help to pay for our monthly outgoings such as the helpline phone bill, charity insurance, domain hosting etc. We really do appreciate your generosity that allows us to keep helping you. Please contact us for details of how to donate by direct debit or visit the TotalGiving site to make donation or sponsor one of our fundraisers.

www.totalgiving.co.uk/charity/kidney-cancer-support-network

Our Fundraisers have been having a great time: Many congratulations to Vicky who organised a Masquerade Ball for KCSN and her local hospice. It was a fabulous evening.



Well done to George & Guy who took part in the Dawn to Dusk challenge.



Roxanne did a 5k muddy race for life followed by a Fun Night at the Musical show with her Mum Kelli and the local drama group.



Another of our members Rhys rode the Birmingham Velo 100 miles in an impressive time of 5hrs 55mins.



Thank You also to the Lost Boys Charity Golf Day and The Wild Duck Braithwaite Grand Reopening — Pictures in the next issue.



Collaboration Between Patients & BMS

One of our members, Jud Hamblin, recently visited Bristol-Myers Squibb, who are pioneering new immunotherapy treatments to fight cancer. During his visit he took part in a staff meeting where he was able to talk about his kidney cancer journey, to help employees better understand a patients' perspective on the disease and its treatment. Jud is pictured with (l-r) Giovanni Caforio (BMS CEO), Ben Hickey (General Manager BMS UK & Ireland) and Johanna Mercier (BMS Head of Worldwide Markets). More details of the aim of such meetings are on our website.

Factsheets

KCSN are currently using the donations raised by our fundraisers to produce our own set of factsheets for the treatment of the three main types of kidney cancer (renal cell carcinoma, transitional cell carcinoma & renal squamous cell carcinoma) & important topics such as genetics & kidney cancer subtypes.

There are many leaflets and booklets on kidney cancer and we have contributed to the excellent Macmillan one which can be downloaded or ordered from:

<https://be.macmillan.org.uk/be/s-666-cancer-type-k.aspx>

Each type of kidney cancer has their own unique characteristics and each is treated differently, making it confusing trying to understand why one treatment, scan or drug is offered to one patient and not another. KCSN is producing in-depth factsheets for patients to understand their disease and the treatment options.

We will be publishing them on our website so look out for info in future newsletters. Also, we would like to hear from you about suggestions for new factsheets.

Facebook Update

The Facebook suite of groups is growing steadily and very busy. With more than 750 members and more than 14,000 posts, comments and reactions each month. There is always someone around to support, pass on knowledge or share a laugh.

Facebook always has a downside and the post a heart to show you care type posts have caused much debate and irritation amongst our members. One member has a response which you can share on your wall next time the daft "show you care" posts do a turn:

www.kcsn.org.uk/opinion-pieces/cancer-patients-riposte-viral-facebook-posts-show-care-cancer

KCSN Wristbands

Raise awareness by wearing KCSN green wristbands. To get yours please make a donation on www.totalgiving.co.uk/mypage/kcsnteam and send an email to us at team@kcsn.org.uk giving your postal address.

The silicon wristbands have our website and our motto "STRONGER TOGETHER"



GOOD LUCK DEBBIE!

One of our members, Debbie, is running the Birmingham half marathon this Sunday in aid of KCSN and Facing up to Kidney Cancer. Please do go and cheer her along. You can see her story and sponsor her via TotalGiving.

We are grateful to John Perrins and his family who asked people to donate to KCSN after his sad death. We wanted to thank all of you so much for the generous donations made to our charity. John was a brave man who fought this disease with courage. Every penny will be put to good use in honour of John.

Contact details: Kidney Cancer Support Network

Website (including patient forums):

Facebook group:

Twitter:

Email support:

Phone support:

Please note that personal views and opinions expressed and any products mentioned are not necessarily endorsed by KCSN. The information contained in this newsletter is not intended to replace advice or medical care from your doctor.

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UK Kidney Cancer Support Network

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If you need this newsletter in a plain text format, please contact us.

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