

Newsletter

Issue 3

www.kcsn.org.uk



Welcome to the third edition for 2017

Our team has been busy since the last newsletter including attending the annual International Kidney Cancer Coalition held this year in Poland, taking part in the Pfizer State of the Nation Workshop in London and talking to both patients and staff at St Luke's Guildford about patient support. We are excited to let you know more details of the first World Kidney Cancer Day and hope you will join in raising awareness of the disease and some social events due to be held.

The Editorial Team

The International Kidney Cancer Coalition 7th Annual Conference

Held at Warsaw in Poland in April, Rose Woodward (pictured right), Julia Black and Sharon Kell represented patients from the UK and were among more than 50 kidney cancer advocates from 28 countries. As a founding member, KCSN took a leading role in proceedings: Julia being one of the organisers and Rose leading a discussion on Supportive Care which covered, amongst others, the fields of pain management, palliative care and shared decision making.

Active patient involvement, clinical trials and real world evidence were among the wide range of topics discussed and talks given. Sharing knowledge between patient advocates and medical teams is vital in helping patients and we need to be part of that discussion. Full details are on the websites (www.kcsn.org.uk and ikcc.org).



IKCC launched the first **World Kidney Cancer Awareness Day** to take place on **Thursday 22nd June**. KCSN will be taking the lead in the UK campaign and hoping to raise awareness across the country.

We would like you to join in the events and to help raise awareness in your locality or nationally. The next newsletter will have full details. Are you willing to be interviewed by local and national press, host a local event or fundraiser? Please do get in touch via team@kcsn.org.uk.

We need to help raise awareness of the causes, symptoms, treatment and research. If people are aware of the symptoms they can get treatment earlier and have better outcomes. Help us to help others. Do also check out our website for further information nearer the day.

<https://worldkidneycancerday.org>

Good News: Kidney Cancer Drug Treatment

Alternative Sutent Dosing Schedule

Some of our Facebook group members have changed their dosing schedule for Sutent and instead of 4 weeks on and 2 weeks off, they are now opting for 2 weeks on and 1 week off. Real world data is now showing that this option is improving patient wellbeing and without affecting the effectiveness of the treatment. If you are suffering from severe side effects then do talk to your consultant about your own situation. Do not change without discussing it first.

Delayed Response with Nivolumab

A recent study has shown some patients who have shown progression whilst on Nivolumab then go on to show signs of significant reduction in tumour burden. It is very encouraging for those who are disappointed with the first scan on treatment.

Phase I trial of antibody drug

Varlilumab is an anti-CD27 antibody and is the first drug of this class to be tested for the treatment of kidney cancer. Further studies are ongoing. Its good to see different types of treatment coming through.

There are further details on these and other important news stories at:

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

Thank You!

To all those who have donated or spent money at easyfundraising to support KCSN work. We really do appreciate your generosity. Just like those donating their new fivers last year, thank you to those kindly donating their new one pound coins. To help us support you, please see the website for how to donate.

Social Events:

Would you like to meet up with other members for a coffee or lunch? If so, please do get in touch. Members of the Facebook group meet up and we welcome everyone along. Recently there was a coffee morning in Guildford with more planned around the country. Details will be on the events section of the Facebook group and on the website.

There are 2 Gala Balls being held this year by members: **Beth Thomas**, who did a parachute jump last year, is organising a Masquerade Ball on the Isle of Man at Empress Hotel on 20th May to raise funds for KCSN and the local hospice. A huge thank you to an amazing young woman. Pictures will be posted online.



Vicky Phelps is also organising a Masquerade Ball to be held on 30th September at Mount Avenue Banqueting Suite, Brentwood in Essex. Again money is being raised for KCSN and the local hospice. Tickets are still available so do get in touch with us if you would like to attend. It is very important to support these wonderful local hospices too.

Many events are currently being planned for the **World Kidney Cancer Day on 22nd June**. If you would like to host an event or help raise awareness of kidney cancer please do get in touch. Full details all events will be in our June Newsletter, on the website and on social media. Please email us on team@kcsn.org.uk if you would like to help out.

**Join us to raise awareness and raise funds
Help us help you.**

My Treatment My Choice

KCSN along with IKCC are launching a decision aid soon for patients with advanced renal cell carcinoma. It is an A4 size booklet explaining options and terminology with spaces for notes and your thoughts. Rose and Julia will be explaining the booklet in full in next months newsletter and we hope that the consultants and clinical nurse specialists will work with their patients using this impressive booklet.

One quote so far: "I wish I had this when I was told my cancer had spread, I could have read it at my own pace and understood better and been able to ask more questions".

Cabozantinib

We have recently heard that, unfortunately, the NICE have rejected the drug Cabozantinib as a 2nd-line treatment for metastatic kidney cancer for the second time. This is despite it's proven effectiveness at prolonging the overall survival and progression-free survival of previously treated kidney cancer patients compared to everolimus in the METEOR trial.

We submitted detailed arguments at both the original submission and the appeal and we have now put in a further appeal and shall continue to fight.

Cabozantinib was designated as a 'Promising Innovative Medicine' by the UK Medicines and Healthcare products Regulatory Agency (MHRA) last year. This indicates that a drug has potential in patients with a poor prognosis and limited treatment options. Until final guidance is published, possibly in August, eligible patients will continue to have access to Cabozantinib via the Ipsen Managed Access Programme in England which is good news.

It is well known that a clinical response to cancer drugs is individual, and some patients respond better than others; KCSN believe that clinicians need to have a choice of drugs to be able to effectively treat kidney cancer. NICE's decision leaves clinicians with a very limited choice, and is denying patients access to a new and clinically effective drug with proven long-term benefits.

KCSN calls upon NICE to review its procedures for the appraisal of drugs for rare and less common cancers. The current appraisal system has proven time and again to be unsuitable for small patient populations, and has been shown to be unfair to rare cancer patients.

If you have any concerns, please get in touch with Rose or Julia at the KCSN (team@kcsn.org.uk).

We shall continue to fight for this and other treatments so please help us.

Guildford Talk & Pfizer State of the Nation Workshop

Lucie Broome, the CNS at The Royal Surrey in Guildford organised an information afternoon and invited Maz Fry to give a talk about the work that KCSN does and the support offered to both patients and carers. The afternoon was completed with very interesting talks by the Consultants and a Dietician which were all well received by everyone who attended.

Rose Woodward, Sharon Kell and Andy Thomas (Chair of KCSN), attended the Pfizer State of the Nation Workshop to discuss how patient experience data can be used to improve outcomes for advanced kidney cancer patients. The meeting was attended by oncologists, surgeons and clinical nurse specialists from NHS England hospitals, and chaired by Professor Sriprasad, consultant urologist at Dartford and Gravesham NHS Trust. More details of both events are on our website.

Contact details: Kidney Cancer Support Network

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

www.kcsn.org.uk
UK Kidney Cancer Support Network
KidneyCancerSupport @KidneycancerSN
team@kcsn.org.uk
01209 890326

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

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.

*** Registered as a charity in England & Wales: No. 1164238 ***