

# Newsletter

Issue 1 2018

www.kcsn.org.uk



Welcome to the first edition for 2018. We have lots of news to share with you: A Gala Ball, news of the 2nd WORLD Kidney Cancer Awareness Day In June, updates on travel insurance and our helpsheets, news of our campaigns, trial results and much more!

*With Best Wishes for 2018 from the Editorial Team*

## WORLD KIDNEY CANCER DAY

We are delighted to announce the **2nd Annual World Kidney Cancer Day** where patient support groups and charities around the world unite to raise awareness of kidney cancer risk factors, detection, prevention and treatment. Last year the campaign led by the **KCSN** was hugely successful across the UK with over 29,000 Twitter 'impressions' and over 50% increase in visitors to our website.

We initiated the '**Go Green for Kidney Cancer**' campaign with some great photos from our members including green lips, nails and hair. Pictured here is Beth, one of our supporters in her lovely hat!

### GO GREEN FOR KIDNEY CANCER on 21st June 2018

Put the date in your diary and join KCSN raising awareness across the globe for kidney cancer. Watch out for more updates between now and June.

# JUNE 21<sup>ST</sup> 2018



### Important Results on Two Trials

The combination of immunotherapy **atezolizumab** (Tecentriq) & targeted therapy **bevacizumab** (Avastin) has been shown to delay the growth of metastatic renal cell carcinoma (mRCC) in a phase III clinical trial called IMmotion151. In the trial, the combination delayed cancer growth by about 3 months compared to standard treatment with sunitinib, another targeted therapy. The benefit of atezolizumab plus bevacizumab was greater for patients with PD-L1-positive tumours.

Results from a phase I clinical trial looking at **CB-839**, a first in class glutaminase inhibitor, in combination with **cabozantinib**, an oral tyrosine kinase inhibitor (TKI), for the treatment of advanced renal cell carcinoma (RCC) have been released. Preliminary results show the combination demonstrated a 40% overall response rate in advanced clear cell RCC patients, and 100% disease control. The safety profile of CB-839 plus cabozantinib was generally consistent with that of cabozantinib monotherapy.

The data for both trials will be presented at the 2018 Genitourinary Cancer Symposium, February 8-10, 2018 in San Francisco, California.



### NICE Submissions

KCSN has already made two comprehensive submissions to NICE this year in support of more treatment options for kidney cancer.

We will keep fighting for all kidney cancer patients and will keep you up to date with all news as soon as we hear it. If you have been on a trial & would like to help us from a patient perspective of a treatment do get in touch: (team@kcsn.org.uk)

We would like to say a **BIG THANK YOU** to everyone who has donated or raised funds for us recently to help us to help you. If you wish to support us please look at the following links. We appreciate every donation.

[www.kcsn.org.uk/support-us/how-to-make-a-donation](http://www.kcsn.org.uk/support-us/how-to-make-a-donation)

[www.easyfundraising.org.uk/causes/kidneycancersupportnetwork](http://www.easyfundraising.org.uk/causes/kidneycancersupportnetwork)

[www.totalgiving.co.uk/charity/kidney-cancer-support-network](http://www.totalgiving.co.uk/charity/kidney-cancer-support-network)

[www.justgiving.com/kidneycancersupportnetwork](http://www.justgiving.com/kidneycancersupportnetwork)



Pictures will be in our next newsletter



Thank You

## Women On the Move Against Cancer

Women On the Move Against Cancer is comprised of volunteers working in the automotive industry, who raise money every year for cancer charities. WOMAC have nominated KCSN as their charity of the year and are holding a Party Wednesday 21st February at The Ashes Suite, Kia Oval, London.

Georgia Fox, Chair of WOMAC, added: 'We are delighted to support the Kidney Cancer Support Network in 2018. The work they do is vital in helping to guide, provide information and support anyone affected by kidney cancer. We are all looking forward to raising awareness for such a wonderful cause.'

[www.womac.co.uk](http://www.womac.co.uk)



## Facebook Groups

The Facebook group is growing rapidly with more than 50 joining already this year and from the group insights there appears to be someone online in the group at all times of day or night so if you cant sleep and just want to talk, someone who understands will reply. Everyone in the group is a patient or carer, no office staff, so do come and join us.

In a poll of the group members, when asked to tell us what the groups mean to them, these words cropped up ⇨

Other phrases were:

Speaking to people who understand what this is like; Inspirational stories of how people cope with RCC; I've only just been diagnosed and joined you, and already I feel less stressed knowing you're all out there; Wish I would of found it sooner; The true meaning of empathy and unwavering support. Always someone there to listen.



## Kidney Cancer Support Network Stronger Together Wristbands

You can get your bracelets by making a donation on our KCSN TotalGiving page:

[www.totalgiving.co.uk/charity/kidney-cancer-support-network](http://www.totalgiving.co.uk/charity/kidney-cancer-support-network)

and then send an email to:

[team@kcsn.org.uk](mailto:team@kcsn.org.uk)

tell us your postal address including postcode and we will send them to you.

Help spread the word and raise awareness.



## Travel Insurance For Kidney Cancer Patients

Its very important to be covered properly - failure to disclose facts may invalidate the insurance for you and everyone in your party. It could prove a very costly mistake. Please check out our factsheet:

[www.kcsn.org.uk/information-hub/patient-to-patient-fact-sheets](http://www.kcsn.org.uk/information-hub/patient-to-patient-fact-sheets)



As well as factsheets on travel insurance, there are also patient fact sheets on:

Nephrectomy Guide; Questions to ask your doctor prior to surgery; A guide to changing TKI dose and cycle frequency; A guide to proper diet with appropriate supplements; Employment rights guide; Management of treatment/TKI side effects in the mouth; TKIs and diarrhoea; Sore hands and feet on TKIs; Personalised cancer medicine; Waiting times for cancer; What is a hospice?

All have been written by patients who know what its like. More fact sheets are being added to the website all the time. Do let us know if you can help.

### 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.

[www.kcsn.org.uk](http://www.kcsn.org.uk)

UK Kidney Cancer Support Network

KidneyCancerSupport

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

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