

New Year, New logo, New website. It's all happening in 2017!



Issue 1 2017

Happy New Year to you all.

Our long awaited new and improved **website** is now live and it includes new elements such as a unique clinical trials hub to support you and help you find out about kidney cancer clinical trials, a patient registry to help collect accurate real world data and discover more stories and information from patients and their families. We have added a guide with this newsletter which gives a taster of some of the information that can be found and we invite you to look at this fabulous new resource. So visit the website and do let us know what you think.

www.kcsn.org.uk

As our **Facebook group** has nearly 600 members, we have expanded the admin team to help our suite of forums to run smoothly. We are very proud that the facebook group is a supportive and confidential place and that all members are either kidney cancer patients, carers or immediate family. Whilst improving—we are also revamping the **newsletters** and are planning short newsletters more often. Do let us know what you would like to read about and if you wish to sign up to receive the newsletters via email at team@kcsn.org.uk

Best Wishes for a happy and healthy 2017

The Editorial Team

Top Tip:

Know when your scan dates and appointments are due and make sure they happen on time. Take control of what you can control.

Nivolumab Campaign

We really need to blow our own trumpet, or more accurately thank Rose Woodward and her team for their persistence and hard work involved in initially getting patients access to **Nivolumab** on the “Early Access for Medicines Scheme” and many congratulations to the whole team for their hard work on the submissions to NICE. **KCSN** was the only charity who provided expert patient witnesses and patient submissions to the original hearing and the appeal. Huge thanks are due to Alison Fielding and Jon Birchall for being such a powerful voice for our KCSN patient community. Thankfully it is **now available to all patients** in England. Another weapon in our arsenal. Our attention is now turning to other drugs and treatments. Do get in touch if you would like to contribute to the fight.

Help us to help you.

STOP PRESS: Everolimus is approved by NICE...see our website for full details. Again congratulations to KCSN for being the only charity to make a submission to NICE.

Clinic Flyer

We have a new flyer to hand out at clinics and events. The eye-catching leaflet shows our website, Facebook group, email, twitter account and our helpline.

Please see our website to download a copy or send us an email to receive copies in the post.

Do spread the word.

KCSN Patient Survey: by Martin Price

Many patients take Tyrosine Kinase Inhibitors (TKI's), a type of biological therapy. Unfortunately, some of the side effects can seriously affect quality of life. This survey of KCSN members looked at diarrhoea and aimed to inform patients about the choice of when to take the drug to minimise diarrhoea. The survey whilst small was representative of many more patients who agreed with responses.

Looking at the relationship between when the TKI is taken and the amount of diarrhoea suffered, the survey found that the majority of patients (82%) favoured taking the drug on an empty stomach (2 hours after food to just before food, or at either end of the day). Of those 57% suffered none to mild diarrhoea. Only 5% of patients took it with food.

Looking at the different drugs: 77% of Sunitinib patients, 44% of Pazopanib patients and 85% of Axitinib patients suffered no or only mild problems. The time most favoured by patients on each drug were: Sunitinib patients at night and Pazopanib patients before food. Axitinib patients were less sensitive to when the drug was taken, which is perhaps fortuitous, since it has to be taken twice daily. This research is helping patients and full details of the survey are on the Facebook group and KCSN website

Thank You!

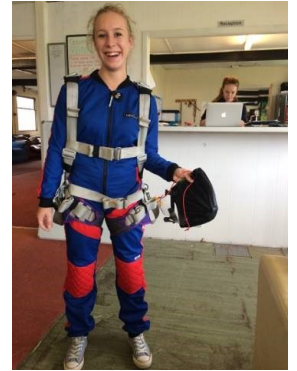
To all those who have joined up to Easy Fundraising and are raising money every time they shop online raising over £600. Details of how to join can be found at:

www.easyfundraising.org.uk/causes/kidneycancersupportnetwork

We would like to thank everyone who has supported KCSN by arranging fundraising events. Most recently David and Bronwen Percival who held an afternoon tea party and raffle for friends. John and Jennifer Perrins arranged a darts tournament with their local pub and David Shutts put forward the KCSN as the CBI Joint Charity of the year.

Our most dramatic fundraising event was Hazel Thomas's daughter Beth who was mad enough to jump out of a plane to raise funds for KCSN and raised an amazing £2100. We would also like to congratulate her on winning the 2016 Clubman British Sidecar Trials Championship. Good luck for the coming season

Thank you also to Charlie who organised a very successful and enjoyable KCSN Ball raising £1800. More pictures are online. Everyone attended had a really good time and enjoyed a raffle and stand up bingo! Do keep your eye on the newsletters and website for details of the 2017 Ball. If any of you would like to help, please do let Maz or Charlie know.



And to everyone for all of the donations that have come in to support our work supporting you and your family. We appreciate your generosity.

If anyone wishes to donate please do so via the TotalGiving website:
www.totalgiving.co.uk/charity/kidney-cancer-support-network

Schrödinger's Cat: My Life on Immunotherapy by Jon Birchall

After 9 months on Nivolumab it's difficult to imagine a time before our fortnightly trips to London from Hereford, or even a time in the future without them...

Thanks to the wonderful support from the Kidney Cancer Support Network we learned that the drug was originally only available under the Early Access to Medicines Scheme. The Royal Free Hospital in London were incredibly supportive in getting me on the programme, and after being briefed about the potential horrors of the drug, and being given fifty pages of potential side effects to read, the treatment commenced.

To read the full story of Jon's journey through this treatment, please read his inspirational motorbike journey around Britain and his amazing blog on his website: facingup2kidneycancer.org

It is well worth getting a cuppa and sitting down for a read.



Travel Insurance

We are often asked about travel insurance and it is very important that you disclose your full medical condition to ensure you do not invalidate your insurance.

Two companies (MIA and insurancewith) have been mentioned by our members as providing good and affordable insurance. Please look on our website for further information www.kcsn.org.uk/forums/forum/kidney-cancer-support-network
If you find another insurance company you would recommend please do let us know.

Do note that normal insurance doesn't cover repatriation or additional hotel costs for patients or carers and family members which could cost many thousands. This is important if hospitalisation is called for in another country or air ambulance home, especially in those countries which rely on patients paying for medical treatments so do insure the whole party not just the kidney cancer patient.

Contact details: Kidney Cancer Support Network

Website (including patient forums):
Confidential Facebook group:
Twitter:
Email support:
Patient helpline:

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