

KCSN Newsletter



Issue 1—Summer 2015

The Kidney Cancer Support Network was founded by Rose Woodward (a kidney cancer patient) and Julia Black (a breast cancer patient and a close friend to a kidney cancer patient) to help kidney cancer patients access the drugs they needed. The aim was to enable patients to share experiences, knowledge and also to raise awareness of the disease and treatments available.

Julia heard Rose campaigning on the radio in 2005 for a drug called Sutent to be made available on the NHS and got in touch. They became firm friends and KCSN was founded.

They helped patients win funding appeals, gain access to their medical records and get lifesaving treatments and importantly gave support and hope when people were faced with the sudden diagnosis of cancer. When NICE refused to fund Sutent, Rose and Julia along with Clive Stone, MBE, mobilised patients & other members of KCSN to lead a protest to NICE in London. Guess who won!

One of the members of the KCSN forum, Sarah Yule, realised patients and carers needed a Facebook group to chat amongst themselves about their personal stories, the highs and lows of living with kidney cancer, swapping tips about treatment side effects and meeting up with online friends. Sadly, Sarah died in 2014.

With hundreds of people being members of the KCSN website forums and the Facebook group, The Kidney Cancer Support Network is a vital lifeline to many patients and their families.

Thank you to Rose, Julia and Sarah.

Summer is nearly here (well so they say) and a lot of people who are ill (and not only those who have cancer) start to ask the question “Will I get travel insurance?”

Two companies seem to crop up time and time again—MIA (www.miatravelinsurance.co.uk) and InsuranceWith (www.insurancewith.com)

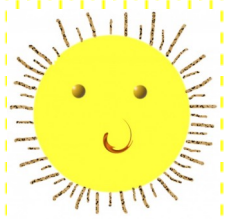
More information can be found here:

<http://www.kidneycancersupportnetwork.co.uk/forum/viewtopic.php?f=13&t=492>

Please let us know if you find any other good ones!

It is wise to note that normal insurance doesn't cover repatriation for patients or carers and family members (children) which could cost many many thousands if hospitalisation is called for, especially in those countries which rely on patients paying for medical treatments.

Good luck and have a lovely holiday :)



Did you know..... the kidneys filter 200 litres of blood every day, enough to fill a large bath-tub, removing two litres of toxins, wastes and water from your body.

Kidney Cancer Support Network: “for patients by patients”

What makes our kidney cancer group different from others? Well for a start we are all kidney cancer patients or carers or immediate family members and everyone in the group has had their life changed to some degree by kidney cancer. This means we truly understand what it feels like trying to cope with the emotional and physical effects of kidney cancer. Everybody in the Network knows the pain, the confusion and the fear a diagnosis of kidney cancer brings with it. When you strike up a conversation with someone else in the group whether it is by a post on Facebook, via email or phone or perhaps as part of one of our organised get-togethers that take place around the country, you know you are really amongst friends who know exactly what you are going through.

Our Facebook group is called a closed group; this means it is a safe and secure place where you can talk in complete confidence to other group members or to our admin team. No-one else can see your posts. We vet & check everyone who requests to join the Network as best we can before we allow them access onto the group page – it’s difficult to believe how many false profiles and scammers or people selling snake oil we flush out each week trying to join our cancer group! We take the security of the group very seriously so if you ever feel your privacy has been breached or you feel something is not quite right with a post, then please send a personal message to one of the admin team and we will sort it out as best we can. This group is a place where you can say things you might find difficult to say to family or friends; where you can ask questions only another patient would know how to answer. You can be angry at what has happened to you or loved ones. You can admit to being scared and worried about what the future might hold. You can grieve with us when a much loved member dies and you can cheer with us when somebody gets a good scan result. You need never feel alone because night or day there is usually someone there to reach out and try to help. One day you might ask for help, but sometimes a few days later you may find yourself offering help to someone else, that is what makes the group unique.

Through sharing our experiences and offering mutual support to each other, we all try to make dealing with this awful disease a bit more bearable for each other. Everyone plays a part and we encourage everyone to contribute to the group in some way. As we say when we welcome a new member into the group “Welcome to the group no-one wants to belong to, but we are glad you found us because we always look after each other”.

www.kidneycancersupportnetwork.co.uk is currently being reviewed to make it much more accessible and to include some new features — but it is a mine of information; you don’t need to register to read the thousands of posts full of interesting facts all about kidney cancer. We have the latest research news, the latest breakthroughs in treatment, patient blogs, right through to chats about digestive issues! If it is about kidney cancer you will find a post about it! And if you want to know something – just ask in either via the website forums or the Facebook group or email us for one to one advice or make a personal call to our helpline; we will do our best to find someone who can give us the answers you need.

The whole ethos of KCSN is about sharing experiences, mutual support and empowering people by providing information. We should be proud of ourselves; patients tell us their lives changed when they joined the group and found genuine support from other patients and carers. We are the largest most active group of kidney cancer patients in the UK and by reaching out to others we all play a part in making sure no-one has to face this awful disease alone.

Some members will be getting together on 26th June at 1.30 at Madison’s Restaurant, Botanic, Belfast —please do pop along if you can! Please contact Jackie Fleming for more info

As stated above, the KCSN is in the process of getting a new web site designed. Until it is up and running, you can subscribe to our newsletters by email by giving us your full name / address / email / and stating whether you are a patient / carer / healthcare professional / other. Subscription enquiries to: team@kidneycancersupportnetwork.co.uk

This is our first attempt at a newsletter. Please feel free to let us know what you would like to see or whether you would like to contribute an article, poem or patient story for the next newsletter in September, thanks :)

Helen's journey..... Up the Pen Y Fan

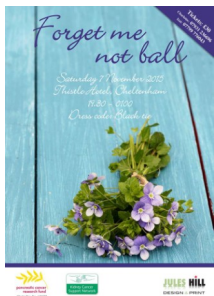


The 30th May was the 3rd anniversary of my nephrectomy and 3 months off me finishing the Sorce Trial. I wanted to do something positive to mark the fact that after 3 years I am still lucky to be all clear. So I decided in a moment of madness to walk up Pen Y Fan mountain in the Brecon Beacons for charity. I had already decided that I wanted our Rose to have half of what I collected for KCSN and the other half to go to Kidney Cancer Research. I spoke to Rose to see if she could point me towards a research fund, she suggested The Renal Cancer Research Fund, so I decided to raise for those two. The walk took place on 31st May, it's a good job the fog was covering the mountain as if I could have seen where I was going I think I might just have changed my mind.... The weather was

horrendous on the way up, hail, heavy rain, gales and fog and I got clapped to the end which was very emotional and I promptly shouted "Up Yours Cancer!" I have to be honest and say I found the walk hard and I may not have been the fastest to get up there but it was a positive thing for me and that if I put my mind to something I can do it. I thought of a lot of people on the way up which kept me going. On the way down the fog lifted and the sun came out, the views were beautiful and if you ever have the chance to go up then I would say go for it. I also got quite emotional with the lovely posts people put on the KCSN Facebook page and I would like to say thank you to you all.... I would like to say thank you to all who supported me and donated.



We have had some wonderful donations made to us over the past year; we are especially proud and honoured by the "in memoriam" gifts sent to us in memory of loved ones which help us continue our work. During the year much hard work has gone into various fundraising events: Sheila Kelly and her amazing vintage tea raised a wonderful amount of money, Angela Battye and the Hope Valley Young Farmers very kindly chose the Kidney Cancer Support Network to benefit from their harvest auction. Pam Cartwright supported our Group and Cancer Research UK with monies from the beautiful jewellery that she makes. Our friends from Christy Watsons charity in Scotland – The Renal Cancer Research Fund, gave us a very generous grant towards our new website and clinical trials and research project. Every penny of the donated money goes directly to providing better patient support and providing better access to information.



Fundraising is ongoing and Charlie, one of our members attends a Ball where each year they raise money for a cancer related charity. The Ball started in 2004 and in 10 years they have raised over £21,500. She put forward our details and we are glad to say that they will be raising money for the Kidney Cancer Support Network. The ball is held in Cheltenham, Gloucestershire and this year will be held on 7th November—if you would like to attend, please contact Charlie — CSKawczynski@aol.com

The Consultation on Proposed Changes to Standard Operating Procedures: The Cancer Drugs Fund for 2015/16

For those members, who like Julia and Rose have strong views about the rights of patients to access clinically effective kidney cancer drugs (and I know some of you are trying to fundraise because you want to be able to access drugs that are currently not NHS funded) you may want to make your views known to NHS England....This is the reminder announcement from NHS England so now is your opportunity to get your views known on The Consultation on Proposed Changes to Standard Operating Procedures: The Cancer Drugs Fund for 2015/16 by visiting the website: www.engage.england.nhs.uk/consultation/cdf-sop-2015-16/consult_view. NHS England wants to hear from anybody with an interest in the Cancer Drugs Fund about the changes proposed to the Standard Operating Procedures.

LATEST RESEARCH

Sharon Kell BSc PhD MBA, a clinical scientist & medical writer has posted several interesting threads to the Kidney Cancer Support Network website. She is working with KCSN as the new website is developed and work is beginning on two exciting new projects – details of which will be in the next few issues of the newsletter.

Amongst the recent new developments are the following 3 articles and for further information please do visit the patient forums on the website. Please also keep an eye out for campaigns to get the NHS to take up these new tests and treatments

Angiotensin Inhibitors may improve survival:

A study has been published in Annals of Oncology showing that metastatic renal cell carcinoma patients on Sunitinib with high blood pressure had longer median overall survival (41.6 versus 16.4 months) and progression free survival (12.9 versus 5.6 months) compared to patients without high blood pressure. In addition, patients taking angiotensin inhibitors for their high blood pressure had significantly better overall survival and progression free survival compared to non-users.

Urine test for kidney cancer:

Researchers at Washington University School of Medicine have developed a urine test to screen for kidney cancer. This test involves measuring the presence of two proteins in the urine; aquaporin-1 and perlipin-2. Raised levels of these proteins in the urine were an indication of the presence of kidney cancer.

Study comparing treatments for non-clear cell Renal Cell Carcinoma:

A study led by researchers at the Duke Cancer Centre in America, has compared Sunitinib with Everolimus for the treatment of rare metastatic non-clear cell renal cell carcinoma (RCC); papillary, chromophobe or unclassified.

The researchers found that Sunitinib was superior to Everolimus at prolonging progression-free survival (the amount of time before tumours regrew), but was more toxic than Everolimus. Sunitinib was more effective for papillary-type kidney cancers and for patients with a better prognosis. Patients with chromophobe RCC and poor-risk tumours had a longer progression free survival when treated with Everolimus than patients treated with Sunitinib.

Understanding your Pathology Report

It is really important to get a copy of your pathology report after your nephrectomy — just ask your consultant or GP, you are entitled to a copy. The pathology report helps you and your consultants plan your future scan timings and any treatment required.

The Leibovich scoring system:

This is a method invented by a Doctor called Leibovich (well that's pretty obvious really!!) who worked at the Mayo Clinic in America. The system is now used worldwide and by some doctors in the UK. It is a mathematical method to calculate the survival / prognosis for kidney cancer patients who are diagnosed with kidney cancer. It is only really relevant to patients who have no evidence of metastatic spread at the time of diagnosis. A score of 0-2 indicates a low risk, 3-5 an intermediate risk and 6-11 a high risk.

Fuhrman system:

Grading refers to the appearance or level of abnormality of the cancer cells under the microscope. The grade gives an idea of how the cancer may behave and is measured on a scale of 1 to 4. A grade 1 cancer is usually slow-growing and is less likely to spread than a higher grade cancer, such as a grade 4.

TNM classification system:

Tumours are categorised by the position and size of tumours and any spread. T relates to the primary tumour size and/or extent, N the lymph node involvement and M to any spread or metastases. Each category is then further subdivided via a number which represents the size and degree of spread. Using these categories the cancer is then classified in stages: Stage I being small and localised within the kidney and in stage IV the cancer has spread to other organs or tissue.

A more detailed explanation can be found at www.kidneycancersupportnetwork.co.uk



Questions arising from the Kidney Cancer Support Network members following the Panorama programme on immunotherapy on 11th February answered by Dr James Larkin

Dr James Larkin, MA FRCP PhD is a Consultant Medical Oncologist at The Royal Marsden who specialises in the treatment of patients with kidney cancer and skin cancers. His research interests include the individualisation of patient treatment in renal cancer and the use of novel targeted therapies and immunotherapies. He is UK Chief Investigator for a number of clinical trials and Chair of both the NCRI Renal Cancer Clinical Studies Group and The Royal Marsden/ICR Committee for Clinical Research. As we make the KCSN into a formal patient-led Charity in its own right, James and other leading healthcare professionals and patients have agreed to become Trustees of our new KCSN patient run Charity. Updates to follow in the next Newsletter !



KCSN: First question should really be - what is immunotherapy and how does it differ from the current standard drugs?

JL: Currently used drugs for RCC (sunitinib, pazopanib, axitinib) mainly attack blood vessels supplying tumours and are non-curative for advanced RCC. They work on average for 8 to 9 months 1st line and are given continuously as long as they are working so side effects are chronic. Immunotherapy stimulates the immune system to recognise and attack cancer so need not be given indefinitely. Experience to date is that if immunotherapy with 'checkpoint inhibitors' (nivolumab, ipilimumab, pembrolizumab) is successful, cancers may be controlled for long periods of time often years. Nivolumab and pembrolizumab have very few side effects.

KCSN: How to access a clinical trial if own Oncologist says "this is not the usual path we would take/recommend?"

JL: Clinical trials should always be discussed and considered. If an oncologist says this ask GP to refer for a 2nd opinion from another oncologist. It is rarely necessary to start treatment urgently for advanced RCC so it is a good idea to get a 2nd opinion and the extra time taken (~2 weeks) is not detrimental.

KCSN: Will these drugs and trials be available throughout the UK, or only at the Royal Marsden? And how will we find out about them.

JL: Immunotherapy trials in RCC at the moment are only open at a small number of hospitals in the UK. JL can provide a list if helpful.

KCSN: Will these trials be available to people who have had two types of cancer?

JL: It depends on the exact details. It is worth checking.

KCSN: What are the known side effects? What is quality of life compared to current drugs

JL: Nivolumab and pembrolizumab have less side effects than sunitinib, pazopanib or axitinib.

KCSN: What are the drugs and their names? Are they all grouped under this heading of immunotherapy or do some immunotherapy drugs do different things.

JL: Another similar drug is MPDL3280A.

KCSN: For those of us with no spleens, would immunotherapy work?

JL: No reason why not.

KCSN: Are they tablets or intravenous? How long is a course of treatment? Are you on these drugs forever like Sutent/Pazopanib etc.?

JL: Intravenous. At the moment in trials the drugs are being given as long as they are working but as per the answer to 1 above it may not be necessary to give them indefinitely. Trials generally cover travel expenses.

KCSN: What are the results so far? Are there articles we can read?

JL: Motzer et al Journal of Clinical Oncology 2014 is an example, but to summarise the data suggest that there is durable benefit from these drugs in about 25% of those with advanced RCC. Combining nivolumab with ipilimumab may increase that to about 40% (Hammers et al ASCO 2014).

KCSN: Will those with rarer forms of RCC be eligible to participate?

JL: The trials generally say 'a component of clear cell histology at present'.

KCSN: What are the trial criteria? Are they phase 1 or 2 or 3 trials?

JL: Mainly Phase 3 at present.

KCSN: What line of therapy do they envision the drugs being, first, second or even third?

JL: Almost always 1st line at present.

KCSN: Could immunotherapy be seen as an alternative for older patients where surgery is not an option?

JL: Too early to speculate on this.

KCSN: Are there any trials planned for papillary RCC now or in the future.

JL: No trials currently open; this is a possibility for the future although early evidence suggests less benefit for these drugs in non-clear cell RCC.

KCSN: I asked last week about nivolumab when I was at clinic but didn't see prof just his registrar. She said only available for melanoma at moment?

JL: incorrect. 1st line Checkmate 214 trial of sunitinib v ipilimumab + nivolumab is open at RMH and other centres.

KCSN: Are these drugs licensed in the EU yet?

JL: No but pembrolizumab for melanoma was 1st drug approved though UK Early Access to Medicines scheme yesterday.

KCSN: How quickly do you see these new therapies becoming available?

JL: If phase 3 trials are positive, approvals for RCC may start in 2017.

KCSN: What level of tumour load would be judged acceptable for using these drugs? How many metastatic sites?

JL: Any level of tumour load and metastatic sites. Main issue is that trials are first line only.

KCSN: Are there any trials that would include sarcomatoid differentiation diagnosis.

JL: Yes, generally just need clear cell component as above.

KCSN: How do we get on the trial if we are not at the Marsden? And what are the criteria? How can we find out more?

JL: Ask for GP referral to RMH. Bear in mind trials 1st line.

KCSN: I was told chemo was not good for kidney cancer; would this be true of immunotherapy drugs as well if not why not?

JL: No we know that immunotherapy drugs can help some patients with RCC.

KCSN: if you had liver cancer & the docking didn't take place on cancer cell & hepatitis started would this intensify liver cancer? KCSN reply - Immunotherapy drugs work well for kidney cancer thankfully, that and melanoma have been about the best responders to old and new immunotherapies (although other cancers such as non-squamous cell lung cancer are now responding to newer drugs like Nivolumab).

JL: Not sure if an answer needed here as there is one already.

KCSN: I don't know if I understood the Panorama programme correctly, I did get the impression that the doctors would need our own individual cancer cells to have individual treatment of individual immunotherapies. If this is the case would they need our primary kidney tumour, or would a fresh biopsy of its metastasis be sufficient to collect the relevant cells? I think that my original RCC tumour is stored in the hospital where I had my nephrectomy. My other question would be: - If the primary tumour is needed to be tested, are these primary tumours stored appropriately, so that they are in a useable condition to test for immunotherapy? And how should they be stored correctly? Hope that makes sense :-))

JL: No problems here. Primary tumours are stored correctly but generally not needed.

KCSN: I would like to know if once the immunotherapy works, can the cancer change its DNA and re-occur, (like it does with these growth inhibiting drugs) or would the body still be programmed to destroy these cells?

JL: Generally with successful immunotherapy the immune system seems to 'remember'.

KCSN: How long before a cure? Will these drugs cure or extend life?

JL: May 'cure' but early days in RCC. Experience in melanoma suggests 'cure' possible.

KCSN: Fascinating programme last night. Is research being done to find ways of preventing immunotherapy drugs from attacking healthy organs/cells?

JL: Yes

KCSN: Are these drugs available after Sutent and Axitinib have been tried?

JL: Not at present; only 1st line.

KCSN: How are these new immunotherapy drugs different from HDIL-2 and interferon Alpha which are hard on the body?

JL: Less side effects.

Contact details: Kidney Cancer Support Network

Website (including patient forums):

www.kidneycancersupportnetwork.co.uk

Facebook group:

UK Kidney Cancer Support Network

Email support:

team@kidneycancersupportnetwork.co.uk

Phone support:

01209 890326



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