



Your Kidney Cancer Support Network Website

www.kcsn.org.uk

KCSN is very proud of its brand new website which is packed full of information. It will be updated with news, advice and developments in kidney cancer research on a regular basis. KCSN also launched The Clinical Trials Database and Patient Registry as well as updated chat forums and support.

Find out about trials which may suit you and help researchers with your valuable real patient data. Real patient stories from our members will make you feel less alone.

This guide gives a taster of what's available and we invite patients, carers and health professionals to all visit the website and do tell us what you think.

This guide provides an insight into what is available with this fantastic new website.



Information Hub

The Information Hub pulls together accurate and up to date information about all aspects of Kidney Cancer: **About Kidney Cancer** covers symptoms, causes, categories of kidney cancer, scans, types of surgery and treatments. All those questions you want to ask when you are first diagnosed.

Access to Treatments and **NICE Guidance** gives advice on how to access the different treatments, the Cancer Drug Fund (CDF) and clinical trials as well as other useful links.

Patient to Patient Help Sheets have been developed by patients and carers from KCSN to pass on the knowledge of those who participate in both website forums and Facebook groups. More will be added shortly.

Glossary & Useful Resources explain all those terms that are bandied about by health professionals and in forums but are often misunderstood by patients and carers. The Useful Resources area provides links to other websites that we hope the KCSN community will find useful.

www.kcsn.org.uk/information-hub

KCSN Community

Your chance to get involved with the charity and to meet other patients and carers through our thriving online communities and regular social events.

Patient Registry: Put your knowledge to good use and help build a good database of experiences (anonymously) to help build up patient-generated data to help researchers with real data on drug treatments.

Patient Surveys: Regular patient surveys help us in our campaigns for better treatments and therapies. The more responses we have, the stronger our arguments.

www.kcsn.org.uk/community

Get Involved

Would you like to help with the charity? We welcome patients and carers to become one of our volunteers. From admin on our Facebook groups to patient advocates or representing the patient voice on a committee or at a workshop, we welcome any help offered. There are social events and newsletters, so always something to help with. The more the merrier. There are details on our website of all the opportunities so please take a look or ask for more information.

KCSN events are organised throughout the country from coffee mornings and lunches to dinners and gala balls. We welcome everyone, including family and friends, so keep an eye on the Facebook group, website and newsletters for information about what is happening in your area.

There are also details of how to help us raise funds to support our work supporting you. Stronger together.

www.kcsn.org.uk/get-involved

Clinical Trials Hub

This section of the website contains everything you need to know about Clinical Trials: What they are, how they are run, which questions to ask, stories of patients who have been on trials and much more.

Trials are vital to both current and future patients. We are grateful to all the patients who have put their trust in their doctors and taken part in previous trials, the scientists and drug companies and of course our consultants, all of whom have enabled the current drugs to be licenced and available on the NHS. So if you and your clinical team are considering changing your medication then do read up and consider taking part in a drug or treatment trial.

The Clinical Trials Database will help you and your doctors find a suitable trial. Patients and carers or clinicians can search for clinical trials that are suitable and taking place in a nearby hospital or specialist centre by searching by their kidney cancer subtype, ie clear cell or papillary, type of clinical trial, location and name of drug. You can then print out trial details for further discussion with your medical team. If you have any queries about how to use the database, email support is available from KCSN.

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

Patient Stories

On the new website there are some genuine stories from some of our members. The aim is to show patients and carers that they are not alone. The stories tell of different treatments, situations, and prospects. Sue is one of those who has agreed to tell her tale:

To give you a little background, I was diagnosed with KC in May last year. Following a CT scan I was told that there was a thrombus in the inferior vena cava, as well as some local lymph nodes – the surgeon was fairly certain that they would not be able to remove all of the lymph nodes & I would require further treatment, with TKIs. The day after surgery....

If you want to find out more about Sue and other patients please visit our website!

www.kcsn.org.uk/community/patient-stories

News Room

Latest Kidney Cancer News and Opinion Pieces: Find the latest news, developments and opinions on all aspects of kidney cancer from healthcare professionals, researchers, patients and carers

Guest bloggers: Many patients and carers blog about their journey which are helpful when a difficult subject is covered. Here we highlight not only patient blogs but healthcare professionals too. If you read a blog that you think others will find interesting or supportive then do let us know so we can add it to the list.

www.kcsn.org.uk/news-room

About Us

Everything you want to know about the teams running or working with us at KCSN:

The Team, The Trustees, The KCSN Medical Advisory Board and other organisations who work with us.

The KCSN Medical Advisory Board is full of eminent medical and clinical oncologists, urologists, radiologists, researchers, nurse specialists and surgeons. It has been established to support the work of our charity and, in particular, the clinical trials and research element of KCSN.

www.kcsn.org.uk/about-us