

Things to remember when researching your case

- KEEP A COPY OF EVERYTHING YOU WRITE TO EVERYONE.
 - TRY TO USE EMAIL WHEREVER POSSIBLE – IT IS SO MUCH QUICKER AND COPIES OF DOCUMENTS CAN BE FORWARDED EASILY.
 - MAKE SURE ALL YOUR LETTERS ARE DATED
 - ALWAYS ASK FOR A WRITTEN ACKNOWLEDGEMENT OF YOUR LETTER
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- THESE RULES APPLY TO EMAILS and LETTERS,
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- IF YOU PHONE SOMEONE; ALWAYS ASK FOR THEIR NAME.
 - ASK THEM TO CONFIRM WHAT THEY HAVE SAID IN WRITING.
 - KEEP A DIARY OR NOTEBOOK AND EVERY TIME YOU PHONE; NOTE THE DATE, WHO YOU SPOKE TO AND WHAT WAS SAID.
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1. Contact your MP. Ask for their support (not just a general letter – be specific). Say “I NEED YOUR HELP BECAUSE YOU ARE MY MP. Will you provide me with a letter in support of my appeal” etc etc. The James Whale Fund for Kidney Cancer website has examples of letters you may want to read. <http://www.jameswhalefund.org>
 2. Ask your GP if they will write a letter to the PCT in support of your case. Your GP probably knows you better than your consultant, he or she should be pleased to help you get the treatment your oncologist wants to prescribe.
 3. We keep saying this... but it is **so important** to get the copies of your PCT exceptional treatment cases /special cases/individual needs policy. This may even be given another name such as unfunded technologies, if necessary put the request in writing, date it & keep a copy, send by email and stress how urgent this is.
 4. Find out from the Cancer Services Department at your own hospital what the name of your CANCER SERVICES NETWORK is. Every Health Authority area has what are called ‘site specific network groups’ in which everyone with a role in urology (urologists, pathologists, oncologist, cancer nurses etc) will meet (a minimum of twice a year) to discuss and record how they will progress complicated cases that require expert attention. They should also appraise locally what they recommend when new technologies become available such as the drugs for renal cancer Sutent and Nexavar. Ask you ‘Cancer Network Director’ to tell you what this Group has decided to do in your area and ask if you have a copy of the minutes where this was discussed and what action was agreed. If it has not been discussed ask for it to be discussed, do this in writing. If it is not made available then say you intend to put in a Freedom of Information request for the information to be made public.

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5. Send the Freedom of Information request (see specimen letter) to your PCT asking about the numbers and their responses to requests for funding of Sutent & Nexavar. You will not get this information by just asking. It will have to be a written Freedom of Information request – experience has taught us that just asking is a waste of time and merely delays getting accurate information about how your PCT funds new cancer drugs.
6. If you feel it would be useful, ask for full and complete copy of your medical records from your hospital (see specimen letter) this will cost £50. But it will have all your records including all notes, scans, copy letters, Dr's comments, pathology reports etc. in it. Ask in writing to your consultant's secretary to be copied in on every letter the hospital sends to anyone about your case/treatment.
7. Ask the PCT how often the Funding panel sits: ask specifically whether this panel will include an oncologist.
8. Ask the PCT what your options are if your application is turned down. ie can you review or appeal to the PCT Board of Directors. Can you attend this appeal personally and put your case. Remember this appeal process may have a time limit on it. ie. you can only appeal within a certain time from the date of the initial refusal.

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KIDNEY CANCER SUPPORT GROUP