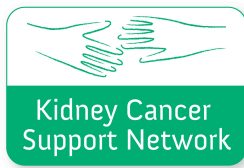
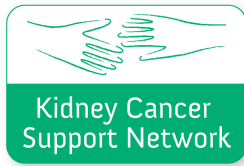


Preparing an Appeal against a PCT Funding Refusal – Step-by-Step help.

1. Join our Kidney Cancer Support Network. Register on the Patient Forum and see if you can make contact with other patients in your local area who have been through the process already.
2. Read through all the leaflets, advice and specimen letters in our download sections and try to familiarise yourself with the process so that you are aware of your rights and how to make sure your appeal is successful.
3. **THE MOST IMPORTANT THING IS TO GET A COPY OF THE FUNDING REFUSAL LETTER. UNTIL YOU KNOW THE SPECIFIC GROUNDS FOR REFUSAL, YOU WILL NOT KNOW WHAT GROUNDS TO APPEAL ON.**
4. Write via email, to the person who wrote the letter of refusal and request **full disclosure** about the way your case has been handled so far you will need the following information.
 - A complete copy of the Minutes of the original application hearing (insert the date of that meeting if you know it).
 - A complete copy of the Minutes from the Appeal meeting (insert the date of that meeting if you know it).
 - Complete set of all documents that was sent to members of the Appeal panel prior to the meeting.
 - A confirmation of the job titles and medical, clinical, and/or other relevant qualifications of panel members of both the original panel and the appeal panel who will be hearing your appeal.
 - A confirmation of whether an oncologist was present at meeting when they refused funding, and a confirmation of who will provide an expert opinion to the appeal process.
 - Copies of the PCT/LHB policies governing the exceptional treatment process including any policy guidance relating to the appeal process.
 - The population base for the PCT area.
 - Copies of any documents or statements about the drug which the PCT/LHB relied on to inform its decision making.
 - Copies of the original application for funding letter or pro forma that was sent to the PCT from your oncology consultant together with the accompanying evidence that (s)he submitted (if any).
 - Terms of Reference for the PCT Appeal Panel and the date those T O R were ratified by the PCT/LHB Board of Directors.
 - Copies of all refusal letters from the PCT.



5. Request all these documents to be sent to you electronically (email) and also hard copy to your home address. **Stress that time is of the essence and until you receive this information you will not be able to prepare your appeal.** Please also ask for an acknowledgement that your request for information has been received. If all else fails, ask for the PCT PALS (Patient Advice & Liaison) office and ask them to urgently take the request for information up on your behalf and come back to you. Again remember to ask the name of the PALS officer you speak to .
6. Your appeal will need to address the individual points given by the PCT for refusal. It is not enough to say, "I need these drugs" or they "the drugs are my only chance" or "these drugs are licensed " or any of the other phrases that we all want to say (because they are true) . If the PCT believed those phrases to be true than they would have given you the drug in the first place. Accept that you will need to argue your case on the specific personal grounds in your refusal letter.
7. Make sure that you have the full support of your Consultant Oncologist, your MP and GP, for your appeal. Ask for copies of their support letters so you know what they have said.
8. Consider writing to the local &/or national media and explaining that you are facing a diagnosis of a terminal cancer and that the PCT have just refused to fund the treatment that your Hospital Consultant wants to prescribe for you.
9. Consider writing a petition for people in your local community to sign and show their support for your situation. Write to us contact@kidneycancersupportnetwork.co.uk for help with wording and templates. We know that local communities & media will support you.
10. Find out the name of your County Councillors who represent you locally; your local County Council will have an Overview and Scrutiny committee; this committee has a responsibility to ensure that the PCTs act reasonably and fairly. Write to your County Councillor personally and ask for their support to get the treatment you need.
11. Ask for a confirmation in writing whether you can present your own case in person at the appeal and state that you do not want such an important hearing to be a paper process.
12. Remember that the PCT MUST consider your personal, individual circumstances and your Consultants professional opinion about your treatment as the basis for their decision. They cannot rely on the fact that N I C E has not approved the drug. They cannot operate a blanket ban on the drug. You need only prove exceptionality **NOT UNIQUENESS**. The PCT can not ask you to prove something that cannot be proved. i.e. that you will respond to the drug better than someone else.



This is just put together from our experience of how the system works and what the various policies and procedures mean to you as a patient applying for funding for Kidney Cancer drugs. It is not prescriptive; it is a general idea about how to **start the process** of appealing or reviewing a funding application refusal. If you have any queries at all and when you have gathered all the above information please email us at contact@kidneycancersupportnetwork.co.uk) and we can talk you through the process. If you have evidence that your PCT did not or are not treating you fairly, then we may be able to get pro bono advice from experienced solicitors and legal team who can advise about your patient rights to a fair hearing.

Rose Woodwood and Julia Black
The Fight for Life Campaign

KIDNEY CANCER SUPPORT NETWORK
contact@kidneycancersupportnetwork.co.uk