

The PCT Appeal Process if you have been refused funding

Your most urgent actions to appeal against a funding approval are :

1. Email or write to the PCT (Primary Care Trust). If you do not have a name , get the name and email for the PCT P A L S (patient advice and liaisons Service) You need to have copies of the application for funding letter or proforma that was sent to the PCT from your Oncology Consultant together with the accompanying evidence that he submitted (if any).

2. Find out when the application was heard, who by and who was on the committee (and what their qualifications are) that heard the application . Ask for a copy of the Minutes of that meeting – you are entitled to see this – it is part of your healthcare record. Find out whether your right to appeal was confirmed to anybody? If not, why not?

3. Get a copy of the PCT published policy for exceptional needs/special cases review and also check if there is a separate policy for appealing against the funding refusal

4. Do a freedom of information request to the PCT to find out how many applications have been made to them and whether they have agreed /accepted ANY funding applications for either Sorafenib or Sunitinib in the years 2006 & 2007 to date. Check with me first because I may have copies of another patient's response which would save time. (specimen letter/template available – please ask if you need this)

5. THE MOST IMPORTANT IS TO GET A COPY OF THE REFUSAL LETTER. UNTIL YOU KNOW THE GROUNDS FOR REFUSAL, YOU WILL NOT KNOW WHAT GROUNDS TO APPEAL ON

6. Check whether your PCT will allow a review of the funding decision as well as an appeal - some do. Check this out and check the answer against their published policy – sometimes the PCT personnel do not know their own policy guidelines.

7. Ask for everything in writing, even if you phone ask for anything anyone says to be confirmed in writing. This is best done by email – if you don't have an email yourself try to find a friend or relative who you trust who can help you. Royal mail will take so long, there are so many questions and things you need confirmed, an email is a blessing in this situation.

8. Ask for a confirmation in writing that you can present your own case in person at the appeal and that you do not want the appeal to be a paper process.

9. If you are unsure about anything to do with your medical/clinical situation then you can get full copies of all your medical records from your local hospital (cost approx £50.00 (specimen letter/template available - please ask if you need this)

10. Find out the names & email addresses of all those likely to be useful in your appeal; MP's Councillors etc. including local media if you want to go down this route.

11. Find out from the PCT whether there has been any statement , policy statement/review/appraisal of Sunitinib and Sorafenib by your local Cancer Network or the S H A or PCT Commissioners which has been used by the PCT to inform their decision

making/prescribing policy on these drugs.(specimen letter available)

It sounds like a lot of work but I'm afraid it is all vital information.
As you know many PCT funding refusals that this is becoming a nightmare situation for so many patients.

As soon as you get all the information, and know where you stand in terms of grounds for appeal then do come back with any other questions. We can then send you more evidence to back up your case.

Please let me know your email address and if you would us to we will add you onto our email list of our Group so that you know the most upto date news and information regarding funding of these two drugs.

We hope this advice will help you - you are not alone. We are just a voluntary PATIENT LED group of Kidney cancer patients who have got together to support each other. We will do everything we can to help you get the drugs that are needed. We can also try to put you in touch with other patients in your area who can talk you through the process and give you support.

ROSE WOODWARD & Julia Black.

The Fight for Life Campaign

KIDNEY CANCER SUPPORT NETWORK

Email - kidneyancernetwork@ukonline.co.uk