

Rachel Maskell MP
House of Commons
London
SW1A 0AA

27th Dec 2017

NHS Individual Funding and Treatment For Rare Cancer

Dear Ms Maskell,

I am writing to you as my MP as I feel that my case represents a wider problem in the treatment of patients with rare cancers.

I have recently been refused Individual Funding for continuation of cancer treatment that I had to go abroad to receive and which worked miraculously well. The funding request was refused for reasons which are unclear to both myself and the two oncologists who have been treating me. The reasons given for refusal (which were not on the basis of cost) cannot be reached from the evidence submitted and so it seems that the Individual Funding Request process has been structured in a way that means patients will never be granted funding.

I'm afraid this is quite a long letter but hopefully I can put across my concerns, my difficult personal position and the wider issues to you so that you can raise it on my behalf with the appropriate minister or ministers.

Background

In early 2014 I was diagnosed with Squamous Cell Carcinoma of the skin, in the middle of 2014 it was confirmed that my cancer had metastasised. Squamous Cell Carcinoma of the Skin is not rare itself but metastasis of the condition is extremely rare.

In late 2014 I went through a series of treatments; surgery followed by seven weeks of daily radiotherapy in conjunction with platinum based chemotherapy. I was treated by Dr {XXX} in York Hospital and also in St James Hospital, Leeds.

This treatment was unsuccessful and in May 2015 I was told that the cancer had spread to my mediastinal lymph nodes, it would continue spreading and that there was no further treatment available other than palliative care. I was given between 3 and 18 months to live and essentially sent home to die.

I decided that there must be something that I could do to help myself and looked at a variety of alternative and natural therapies. These and the saga as a whole are documented in my blog; <http://www.tryingtobeatcancer.org.uk>.

Immunotherapy

The various things I did seemed to slow the spread of the cancer but not actually get rid of it. In late 2016, my wife and I became aware of a treatment called immunotherapy and after some research we found that a drug called Pembrolizumab had been used in the United States with extremely good results on my form of cancer and other similar cancers.

We found that this was approved for use in the NHS for similar cancers to mine and so approached my oncologist requesting treatment with this drug, it was refused as the drug is not licensed in the UK for use on my form of cancer. We offered to fund it ourselves but again we were refused.

I requested a second opinion and in late January 2017 saw a Professor {LLL} at The Royal Marsden in London (for 15 minutes), he told me access to immunotherapy drugs was difficult, it was unlikely to be successful (less than 20% chance) and said his recommended treatment was platinum based chemotherapy. (See enclosed letter)

In January 2017, through an article in The Times, we heard of a clinic in Germany that was treating a number of UK patients who had been told by the NHS that no treatment was available and so were self-funding their treatment. We contacted the clinic and also contacted some of the other patients to check the clinic was above board. The clinic requested my previous scans and my tissue samples and told me that there was a good chance they could cure me. The treatment was however extremely expensive, after some discussion over the financial aspects we decided to try it and if it didn't work after a couple of treatments we would give up and I would accept my fate.

The Hallwang Clinic in Dornstetten, Germany uses extremely up to date, possibly experimental, treatments to try and cure otherwise written off cancer patients. I had hoped to be treated with Pembrolizumab but they put together a treatment plan of Pembrolizumab in combination with Ipilimumab and a vaccination strategy together with various infusions. I arrived for treatment in early March 2017 and the consensus was that I would be lucky to survive long enough for the treatment to work (it is usually 4 to 6 weeks before it has an effect). I was treated at the clinic for a week.

The treatment began to work in less than 3 weeks; tumours on the surface of my body began to disappear overnight. By coincidence I had an appointment with my NHS oncologist just before I was due to return to The Hallwang Clinic for a second visit. He was able to examine me and noted that tumours

which he had examined in January 2017 were now not present on my body. I discussed my treatment at The Hallwang Clinic with him, he was curious but not particularly interested.

I attended the Hallwang clinic a further 4 times for treatment as that was considered the minimum course of treatment with the 2 drugs. In 3 months I recovered from barely being able to climb my stairs at home to feeling fit and well again.

The treatment at The Hallwang Clinic cost me around £170,000 including travel, accommodation and subsistence. My wife and I are not poor but neither are we wealthy, but we have been prudent and saved for our retirement. Because I was terminally ill I was paid my Army pension early, my gratuity went towards my treatment. I also had a personal pension plan of around £100,000 which I emptied and spent on my treatment, the rest of the money was raised from savings and by selling possessions.

When I returned from the Hallwang Clinic in June I was unsure of how to progress, the clinic wanted me to keep attending every 3 weeks but each visit was costing me £25,000 so I couldn't really afford it. I had been surprised at the lack of interest anyone in the medical profession had taken regarding my recovery and so I identified and wrote to over a dozen medical experts in the UK who were researching both immunotherapy and skin cancer to try and get somebody interested in my case. I had only one positive reply from Professor Johnson at Southampton University Hospital who invited me down to visit his immunology team.

Recent Developments

I travelled to Southampton and back from York on 29th June 2017 to see Professor {ZZZ}, a 10 hour round trip. He requested my previous scans from both Germany and Leeds and discussed possibly continuing my treatment at Southampton if necessary. I had had a PET CT scan in March 2017 in Germany to act as a baseline to measure my response to treatment. I had another PET CT scan in Leeds on 14th July 2017.

The scan in March 2017 showed tumours in every major organ of my body apart from my lungs and liver; they were also in my arms and legs and throughout my lymph node system; I had 3 in my brain. The scan in July 2017 showed some low level activity in the mediastinal lymph nodes; some activity in my left lung hilum and some small activity in my large intestine. Everything else had gone. These scans can be seen and compared on my blog at <http://tryingtobeatcancer.org.uk/scan-results-before-and-after-treatment/>

Professor {ZZZ} suggested I continue for a further course of immunotherapy treatment, the arrangement being that I would be treated as an NHS patient but would self-fund the drugs. I agreed and have been treated at 3 weekly

intervals in Southampton since September using the dosages given in Germany as these worked and I have had few side effects.

Individual Funding Request

Because the course of treatment at Southampton was clearly defined the costs were known, so I asked my Leeds oncologist, Dr {XXX}, to apply for NHS funding using an Individual Funding Request (IFR) based on these costs.

Both Dr {XXX} and Professor {ZZZ} told me that applying for funding was a waste of time as it is never granted, nevertheless I insisted because the process is there so it should be tested.

In addition a reporter on Look North (Tyne Tees) had covered my story along with another person's and had asked NHS England why these drugs could not be provided on the NHS, NHS England replied that we should apply for individual funding. The broadcast piece can be seen here:

<http://tryingtobeatcancer.org.uk/appearance-look-north/>

Dr {XXX} submitted an excellent request for funding (enclosed) on the basis of my exceptional situation; a recovery from a usually fatal condition due to drugs that would not normally be used by the NHS on that condition and the likelihood that it would cure me of cancer given my previous excellent response. The amount requested was £31,500, not a great deal to the NHS but a considerable amount to me. The submission was approved by the local panel(s) in Leeds and then refused by the "IFR Screening Group", it never reached a national panel.

I received a copy of the letter refusing the request (enclosed) but the reasons given for the refusal seemed to make no sense and bore no relation to the information submitted by my oncologist with the request. Essentially they said I was not exceptional enough despite my oncologist stating in the application that I was "unique in the UK".

I contacted Dr {XXX} to ask him for an explanation, he was also unable to explain the group's reasons. So I wrote to the IFR Screening Group (enclosed) asking for an explanation. After over three weeks they responded (enclosed) to say it is my oncologist's responsibility to explain to me the reasons, but as he was unable to, he must write to them, so they can reply to him, so he can explain to me. This seems both ridiculous and expensive in terms of the time it will take up of a busy oncologist and an NHS department and it also does not allow for the case of me having further questions.

Issues raised

There are a number of concerning issues raised by my experience which is by no means unique.

1. Immunotherapy drugs only become available to NHS patients after a lengthy process involving clinical trials. For this reason they will never be generally available to patients with rare cancers because there are simply not enough patients to enable a clinical trial to be held or for the results to be relevant.
2. Neither the NHS nor the pharmaceutical industry are interested in patients with rare cancers. The NHS aren't interested as even if they cured every patient in the UK with a rare cancer it wouldn't make the tiniest dent in the overall cancer statistics, so they don't bother. The pharmaceutical industry are not interested as they are unlikely to recover the costs of a clinical trial necessary to get a drug licensed and would never make any money due to the low number of patients to be treated.
3. For the above reasons the Individual Funding Request (IFR) system is often the only route to treatment for those with rare cancers and yet almost always fails them. This issue has been highlighted for some time now since cancer drugs funding was changed. A good example can be found here: <http://www.kcsn.org.uk/opinion-pieces/confusion-individual-funding-request-ifr-system/>
4. The IFR process and particularly the IFR Screening Group seem to have been engineered to make it almost impossible to gain funding for treatment. There is no redress to the IFR Screening group and they do not seem to be accountable for or have to explain their decisions. A decision by a national panel can be subject to review but not the screening group's decisions. The process is set out here: <https://www.england.nhs.uk/wp-content/uploads/2017/11/ifr-standard-operating-procedure-nov-17.pdf> and a diagram of the process is here: <https://www.england.nhs.uk/wp-content/uploads/2017/11/ifr-infographic.pdf>
5. The fact that both the oncologists involved in my treatment told me that making an IFR was a waste of time shows that clinicians have no faith in the IFR system either. Applying for funding takes up a considerable amount of a clinician's time, which is not something they have a lot to spare, so it is not surprising that given the low chance of an IFR succeeding, they are reluctant to engage in the process. This is borne out by figures provided in response to a written question in parliament in March this year which shows that IFR submission is reducing significantly year on year and around two thirds of applications are refused by the IFR Screening Group (where there is no redress). <http://www.parliament.uk/business/publications/written-questions-answers-statements/written-question/Commons/2017-03-01/66178/>

6. The IFR process is extremely long winded and seems to involve a vast amount of people:
 - a. Almost every decision making team at the local Trust level.
 - b. A department set up solely to review requests that have been approved by those involved in the treatment of the patient
 - c. A national panel that must be convened specially.The cost of this process must be extremely high given those involved, in my case it is likely to exceed the requested cost of the treatment necessary to save my life.
7. The care and wellbeing of patients seems to have become a much lower priority than the cost considerations of treatment, it does not seem to have been considered at all when refusing my IFR.
8. As soon as a patient is deemed to be terminal it is obvious to me that the budget for that patient is instantly restricted. The NHS is far too quick to give up on patients they consider terminal in order to save money. In my experience the NHS continues to ignore patients even when they are recovering. My treatment essentially stopped on being declared terminal; I had to push to get regular scans and had to almost demand treatment when I needed it.
9. The UK appear to lag behind other countries in both research into and implementation of new cancer drugs. The NHS seems to wait for the FDA in the US to approve a drug before considering it for use, they then require the pharmaceutical companies to carry out clinical trials (duplicating the work in the US) before licensing it. We soon realised that we knew more about immunotherapy than our oncologists when we raised the subject and found out more about immunotherapy by using Google than we would ever have found out from the NHS.
10. There is a growing number of terminal cancer patients seeking treatment outside the UK because they have been told there is no further treatment available to them and/or refused access to potentially lifesaving drugs. Many are successfully treated, the majority that I have met had rare cancers. Many people cannot afford the cost of treatment abroad and so attempt to raise the money via crowdfunding. For those that raise the money, their situation is exacerbated if their treatment is successful as the NHS simply refuse any further treatment to them by interpreting the extremely open NHS guidelines in such a way as to save money rather than people. I have been lucky to find treatment in the UK but I know of a number of patients who have had no choice but to seek treatment abroad and on returning find that their local NHS Trust simply refuses them any treatment whatsoever. The position they are left in is the same as mine; if they cannot afford to continue private treatment their only option is to die, they are condemned to death by the NHS.

11. Trusts around the country seem to interpret NHS guidelines in vastly different ways. Southampton are extremely proactive in treating cancer and are happy to allow patients to fund their own drugs if they are not available on the NHS and can be shown to be beneficial, Leeds apparently will not. Thus I am having to travel the length of the country incurring large travel and accommodation expenses, to receive treatment that is being routinely administered in St James Hospital, Leeds on the NHS. The only reason for this is that in Leeds they interpret the guidelines differently to Southampton and so will not allow patients to self-fund lifesaving drugs, even though they acknowledge that these drugs could save their lives. In my case Leeds has agreed that my case needs funding from the NHS, they have agreed to take on my continued treatment if funded by the NHS, but will not provide me with the treatment if I fund it myself. I find this bizarre.

Being diagnosed with cancer and trying to stay alive is quite stressful, yet stress is not a good thing for people with cancer. Having to spend most of the last three and a half years correcting errors made within the NHS, having to almost plead to get treatment and regular scans after being told I was terminal, then finally having to worry about how long I can continue to afford the treatment that is obviously saving my life, has been extremely stressful and has not helped me fight this condition. Many people describe having cancer as a battle, my experience is that most of that fight is with the NHS. So far I have been written off three times by the NHS.

Possibly the most worrying thing of all is that hardly anyone has shown any interest in my response to readily available drugs or my incredible recovery which, to me, is nothing short of a miracle. Nothing has been learned from my experience that could help others.

The Immunology team in Southampton had hoped to gain some information about what was going on in my body and immune system but unfortunately (for them) I have no accessible tumours left to perform a biopsy on. I have taken part, voluntarily in a research project that Professor {ZZZ} is undertaking, but still feel that the opportunity for furthering cancer treatment from my experience has been lost because nobody took any interest earlier in my recovery despite being fully aware of it.

I have served my country and have the medals to prove it and I have paid into the tax and National Insurance system for over 40 years. So the situation I find myself in; i.e. that I will possibly only survive as long as I can afford to pay for my own treatment, to be obscene, I feel abandoned. £31,500 is a pittance for the NHS to fund, they would probably have spent more on me if they had given me palliative care and then put me in a hospice. It is even more galling when I read almost daily of the waste of public funds by elements of the NHS and the amount of compensation paid out yearly for avoidable mistakes. The most recent case of NHS wasting

money is that they apparently spend £4.5 million per year on anti-dandruff shampoo. <https://www.thetimes.co.uk/article/treating-dandruff-takes-millions-from-vital-care-nhs-chief-simon-stevens-warns-qh1k0r50z>

I hope you find something in this letter which you think is of concern and can take the matter up for me. It is extremely difficult for me to fight for my treatment whilst dealing with this illness and the various ways it impacts my life. If you need any further information please do not hesitate to contact me.

Yours sincerely

Paul Thomas-Peter

Enclosures

1. Letter dated 25 Jan 2017 from Dr {LLL}, The Royal Marsden Hospital
2. IFR form with associated Clarification of Exceptionality dated 25 Sep 2017
3. Letter from IFR Screening Group dated 17 Oct 2017
4. Letter to IFR Screening Group dated 3 Nov 2017
5. Letter from IFR Screening Group dated 29 Nov 2017