Personal statement by Paul Sharp in support of The James Whale Fund for Kidney Cancer in Scotland

Convener and committee members

Following our conversation at the meeting on 22nd November at Holyrood (Patient access to innovative medicines and the role of Individual Patient Treatment Requests (IPTRs)) can I thank you for the invitation to submit a personal statement for the consideration of your committee. In this short statement written from a patient’s viewpoint, I would like to highlight the current issues surrounding the provision of drugs to kidney cancer patients in Scotland. Kidney cancer is the 8th most common cancer in the United Kingdom with a higher than U.K. average incident rate amongst the Scottish population.¹

My name is Paul Sharp (51) and I have advanced kidney cancer. In 2010 following initial diagnosis and removal of my left kidney, I took part in a clinical trial (SORCE²) for the drug Sorafenib. Unfortunately, metastatic cancer occurred and in 2012, I was removed from the trial and began treatment by the Scottish Medical Consortium (SMC) approved 1st line drug, Sutent (Sunitinib).

In my personal experience and further to many detailed and emotional conversations with fellow patients, I feel that areas of concern exist that are worthy of your attention. I do of course realise the current challenging economic environment and the difficulties facing the SMC in structuring the finite funding to best possible effect, but I would be neglecting the extremely strong feelings of my fellow patients and their families if I did not highlight those concerns to you and your committee:

- Access to approved drugs
This continues to be a priority topic and one that occupies a great deal of patients' time for obvious reasons. The current lack of any approved kidney cancer drug (past the previously mentioned Sutent) is a constant worry. Medical documentation from across the world reveals national cancer protocols with access to 2nd and 3rd line treatments continues to cause much

¹http://www.jameswhalefund.org/editpics/File/JWF_FactSheet_Kidney_Cancer_Statistics%20_UK.pdf
²http://www.ctu.mrc.ac.uk/research_areas/study_details.aspx?s=31
angst amongst patients in this country and migration to another U.K. country to seek further treatment is not unknown. I would urge the committee to continue to work towards provision of suitable drugs for 2\textsuperscript{nd} and 3\textsuperscript{rd} line treatment and continue in aspiring to be a nation that provides the best possible health care for its citizens.

- **Individual Patient Treatment Requests (IPTR)**  
  Research shows that there would appear to be a lack of applications (and successful outcomes) from oncologists to the SMC requesting an IPTR. Success rate across Scotland also appears to be variable across NHS areas and the reasons for this, be it oncologist’s available time to complete the supporting documentation or the perceived poor likelihood of success, would surely benefit from further examination with a view to ensuring a common approach to the submissions process across Scotland.

- **Available trials**  
  From a patient’s perspective, clinical trials provide a multiple benefit to the cancer community; obtaining valuable research provides essential progress data on drug development, potential clinical improvement to the patient and more importantly, provides hope for those whose treatment pathways are limited. I realise that this area is not straightforward but I hope that the Scottish Government can continue to work closely with pharmaceutical companies in an honest and transparent way, considering innovative ways to work in partnership (such as joint ventures) and increase the opportunities to trial for the benefit of patients and families. Studies (and personal experience) have shown that patients on clinical trials have shown improved mental health and clinical outcomes. There does appear to be a lack of oncology trials compared to other trials areas with something as minor as lack of administrative support\(^3\) appearing to be a barrier to success. I would strongly suggest that the positive offset costs of individuals (and their carers) continuing to work and fully participate in society should be of significant interest to the committee and that an increase in oncology trial programmes could be looked at.

- **Continued engagement**  
  I very much hope that you and your committee will continue to work with patients’ charities who do so much good work in supporting those with cancer, in particular, for those of us with kidney cancer; The James Whale Fund\(^4\) in Scotland provides much information and personal support and with Renal Cancer Research providing targeted research funding in Scotland\(^5\), we are served by two very good sector specific groups.

Before closing, can I please highlight to the committee the excellent support and care extended to me by the NHS medical community as I work through my treatment, XXXX and XXXX deserve particular credit in creating a

\(^3\)http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2033847/  
\(^4\)http://www.jameswhalefund.org/  
\(^5\)http://www.renalcancerresearch.org/
comprehensive care and treatment centre of excellence for XXXX. The nursing staff employed there are of the highest calibre providing an essential and professional support to anxious patients and dealing with the challenges arising with genuine compassion and care, a credit to their profession.

The existing system provides the firm foundations with which to build a potentially comprehensive and world beating cancer care system for the nation of Scotland, it can be done but it needs the full concentration of the Scottish Parliament’s Health and Sport Committee to enhance and improve these foundations and make the difference for kidney cancer patients in Scotland.

I submit this personal statement in the hope that it can provide some contextual support to the debate on licensing and processing of new medicines in Scotland.

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