



Cynulliad National  
Cenedlaethol Assembly for  
Cymru Wales

## **The Petitions Committee**

### **Completion Report**

**Summary of the Petitions Committee's consideration of  
P-03-196 Availability of Sutent**

**March 2009**

**Petition Received**

16 December 2008

**Ruled Admissible**

17 December 2008

**Initial Consideration****13 January 2009**

The Committee gave initial consideration to the petition and agreed to:

- Ask the Minister for Health and Social Services for an update on the action she has taken, including any submission she has made to the National Institute of Health and Clinical Excellence (NICE) in relation to Sutent (sunitinib) and whether she is aware of action taken by the UK Secretary of State for Health. The Committee has also asked the Minister to provide us with the findings of the clinical audit she has commissioned of decisions made by Local Health Boards and NHS Trusts on access to drugs used to treat kidney cancer and an indication of when the audit will be available
- Write to the National Institute of Health and Clinical Excellence to ask for an update on the current position on guidelines for Sutent (sunitinib), and that it provides the Committee with its findings in relation to Sutent (sunitinib) as soon as they are available

(See Annex 1 for the relevant extract from the transcript of the meeting on 13 January 2009, Annex 2 for the letter sent to the Minister for Health and Social Services and Annex 3 for the letter sent to the National Institute of Health and Clinical Excellence)

**10 February 2009**

The Committee considered responses from the Minister for Health and Social Services and the National Institute of Health and Clinical Excellence and agreed to conclude its consideration of the petition as its objectives have been met.

(See Annex 1 for the relevant extract from the transcript of the meeting on 10 February 2009, Annex 2 for the response received from the Minister for Health and Social Services and Annex 3 for the response received from the National Institute of Health and Clinical Excellence)

**Petitions Committee Clerk**  
**February 2009**

## **Annex 1**

# Transcripts of Petitions Committee meetings

**13 January 2009**

**Val Lloyd:** The last of the new petitions, P-03-196, is on the availability of Sutent. To some extent, this has been overtaken by events since the petition was handed in. It came from Joanne Popham, who collected over 8,000 signatures. It was prompted by her father's situation. Does anyone wish to take this forward?

**Bethan Jenkins:** I received this on behalf of the petitioners just before Christmas. I do not think there had been any progress at that date. We should ask the Minister to inform us when the findings of the clinical audit are finalised, and perhaps we could write to the National Institute for Health and Clinical Excellence to keep us updated on progress—as well as informing the petitioners, of course.

**Val Lloyd:** NICE published its guidance after this petition came in.

**Bethan Jenkins:** Right.

**Val Lloyd:** It changed the guidance so that Sutent is available much more widely. So, there is no longer any need to write to NICE. That would have been necessary at the time when the petition came in.

**Bethan Jenkins:** I thought that it was just the Minister's—

**Val Lloyd:** No—NICE has changed its guidance. It issued supplementary guidance and we are waiting for a further ministerial comment on that, but she has moved her position as well.

**Bethan Jenkins:** She has announced the audit, has she not?

**Val Lloyd:** Yes, she has announced the audit, but she has gone a bit—

**Michael German:** What I think that we need to establish is what action the Minister in Wales has taken given the NICE report that was published over the Christmas break.

**Val Lloyd:** It was in the new year, but very early on.

**Michael German:** We also need to establish what action the UK Government Minister has taken, and what action our Minister intends to take in respect of the new NICE guidance.

**Val Lloyd:** The audit will stand because she has asked for it. It was across the local health boards, because there was a lack of consistency. That was why the Minister called for the audit, but it has been overtaken by the guidance.

**Michael German:** Could we also ask for the timescale of the audit?

**Val Lloyd:** Yes, certainly.

**10 February 2009**

**Val Lloyd:** The last petition is on Sutent, which is P-03-196.

**Michael German:** The petition is what has done it again with this one.

**Andrew R.T. Davies:** The petitions are working well.

**Val Lloyd:** We are agreed that we will close this petition in view of the availability now of Sutent. That completes our update on petitions.

## **Annex 2**

## Y Pwyllgor Deisebau

### Petitions Committee

Edwina Hart AM  
Minister for Health and Social Services  
Welsh Assembly Government  
Cardiff Bay  
CF99 1NA

Bae Caerdydd / Cardiff Bay  
Caerdydd / Cardiff CF99 1NA

Our ref: PET-03-196

19 January 2009

Dear Edwina

#### **Availability of Sutent (P-03-196)**

The Petitions Committee is considering a petition that believes that it is:

"irrational and cruel for kidney cancer patients to be forced by Local Health Boards through long and complicated exceptional cases/appeal process to be told they can not receive the treatment their oncologist wishes to prescribe them."

The petition calls for the Welsh Assembly Government to:

"give their personal assurance that they will do everything in their power to make Sutent available to these patients today."

The Committee is aware that you have taken a keen involvement in this issue. We would therefore welcome an update from you on the action you have taken, including any submission you have made to the National Institute of Health and Clinical Excellence (NICE) in relation to Sutent (sunitinib) and whether you are aware of action taken by the UK Secretary of State for Health. We would also be grateful if you could provide us with the findings of the clinical audit you have commissioned of decisions made by Local Health Boards and NHS Trusts on access to drugs used to treat kidney cancer and an indication of when the audit will be available.

Thank you for your consideration of this matter, and I look forward to your response.

Yours sincerely



**Val Lloyd**  
Chair, Petitions Committee

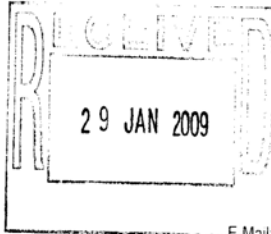
**Edwina Hart AM MBE**

Y Gweinidog dros Iechyd a Gwasanaethau Cymdeithasol  
Minister for Health and Social Services

Our ref: EH/00193/09

Your ref: PET/03-196

Val Lloyd AM  
National Assembly for Wales  
Cardiff Bay  
Cardiff  
CF99 1NA



Llywodraeth Cynulliad Cymru  
Welsh Assembly Government

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*Dear Val*

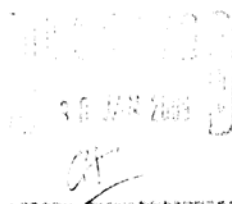
29<sup>th</sup> January 2009

Thank you for your letter dated 19 January about the Petitions Committee's consideration of the petition submitted on behalf of Mr Paul Popham, about the availability of Sutent for the treatment of renal carcinoma (P-03-196).

You will wish to be aware that, at my request, the Deputy Chief Medical Officer, Professor Mike Harmer, wrote to Local Health Boards (LHBs) on 22 January, instructing them to make the drugs bevacizumab (Avastin), sorafenib (Nexavar), sunitinib (Sutent) and temsirolimus (Torisel) available to suitable patients with immediate effect, providing that each request for funding for the life-prolonging drugs is supported by two cancer specialists.

This is a temporary arrangement that will be in place until NICE make their final decision on these drugs, and has been done to allay the anxiety felt by patients and their relatives during this interim period.

Professor Harmer is also carrying out the clinical audit that you refer to in your letter. This work is looking at the processes used by LHBs in the consideration of requests for Sutent, including the appropriateness of the request. I expect to receive his report in the next few weeks.





## **Annex 3**

## Y Pwyllgor Deisebau

### Petitions Committee

Andrew Dillon  
Chief Executive  
The National Institute of Health and  
Clinical Excellence  
Mid City Place  
71 High Holborn  
London  
WC1V 6NA

Bae Caerdydd / Cardiff Bay  
Caerdydd / Cardiff CF99 1NA

Our ref: P-03-196

19 January 2009

Dear Mr Dillon

#### **Petition on availability of Sutent**

The Petitions Committee of the National Assembly for Wales is considering a petition that believes that it is:

"irrational and cruel for kidney cancer patients to be forced by Local Health Boards through long and complicated exceptional cases/appeal process to be told they can not receive the treatment their oncologist wishes to prescribe them."

The petition calls for the Welsh Assembly Government to:

"give their personal assurance that they will do everything in their power to make Sutent available to these patients today."

The Committee is aware that NICE has produced initial guidance on the funding of Sutent (sunitinib) by local health boards and that you are in the process of issuing new guidelines. We would therefore welcome an update from you on the current state of play and a copy of your findings in relation to Sutent as soon as they are available.

Thank you for your consideration of this matter, and I look forward to your response.

Yours sincerely



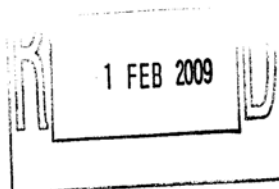
**Val Lloyd**  
**Chair, Petitions Committee**

C.c. Dr Carole Longson, Director, Centre for Health Technology Evaluation

29 January 2009

**NHS**  
**National Institute for  
Health and Clinical Excellence**

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Val Lloyd  
Chair  
Petitions Committee  
National Assembly for Wales  
Cardiff Bay  
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Dear Ms Lloyd,

**Petition on the availability of Sutent**

Thank you for your letter of 19 January 2009.

As you know, Edwina Hart announced recently that Sutent and the other 3 drugs for treating renal cancer, which are currently being appraised by NICE, are to be made available in Wales with immediate effect.

We will publish the outcome of the independent advisory committee meeting, held on 14 January, which will set out the Institute's current position on the use of these treatments, within the next 3 weeks.

I hope this information is sufficient for you at this stage.

Yours sincerely,

Andrew Dillon  
Chief Executive

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14 FEB 2009  
GDI