From: [redacted] [[redacted]]
Sent: 19 November 2008 14:51
To: Jeremy Powell
Subject: Petition Regarding The Draft Recommendation on Revlimid
Date: Wednesday 19th November 2008

Dear Jeremy

This is my response to the draft recommendation on Revlimid

In response to section 1

a.. Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma ('M'). To reject it purely on cost alone is wholly inappropriate – solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the M community implore NICE, the Government & the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patients

b.. For patients to know that there is a licensed, clinically effective treatment out there but that they cannot have it is a cross they should not have to bear

c.. A failure by NICE to reconsider its draft will make it increasingly difficult for patients to get access to this important advance in the treatment of M.

d.. The rarity and severity of M brings with it a number of challenges for which there is currently no formal way of dealing with in the UK. The recently announced NICE consultation on appraising higher cost treatments for rarer diseases is extremely welcome, & we urge that any new reforms that come out of the consultation will apply to Revlimid

In response to section 2

a.. Revlimid is the first myeloma treatment to be developed where the balance between clinical effectiveness and side-effects is excellent, so much so that patients can remain on it longer term

b.. Revlimid is a convenient treatment for patient and their families. Oral dosing does not involve the resource and time-intensive visits to the hospital– patients can self-medicate at home or at work

c.. NHS access to Revlimid would ensure that myeloma patients have treatment options even when they are refractory to other therapies, and will help them live longer to benefit from future developments

d.. Revlimid offers therapeutic options to patients to get back into remission, improving their overall survival and helping them lead an increasingly independent life

e.. The Government now say that patients can pay for treatments out of their own pockets if the NHS does not provide them. Revlimid costs £4368 per month; Aricept (to treat early stage Alzheimer's) costs £75 per month. Both are currently rejected by NICE. It is clear that where a treatment costs only a few pounds a day, 'topping up' is unlikely to prove a serious financial burden vs. treatment costing thousands of pounds every month, will be affordable to very few people. If it remains rejected by NICE, the financial burden on the vast majority of myeloma patients who are suitable candidates for Revlimid would be unmanageable

This text wouldn't all quite fit into the online petition which is why I have emailed it.

Kind regards

[redacted]

Member of the general public

From: [redacted] [[redacted]]
Sent: 13 November 2008 11:47
To: Jeremy Powell
Subject: Petition Regarding The Draft Recommendation on Revlimid

Dear Jeremy

This is my response to the draft recommendation on Revlimid

In response to section 1

a.. Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma (‘M’). To reject it purely on cost alone is wholly inappropriate – solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the M community implore NICE, the Government & the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patients

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Kind regards

[redacted]

Member of the general public

From: [redacted] [[redacted]]
Sent: 15 November 2008 23:50
To: Jeremy Powell
Subject: Petition Regarding The Draft Recommendation on Revlimid» quick replysend
Dear Jeremy

This is my response to the draft recommendation on Revlimid

In response to section 1

a.. Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma ('M'). To reject it purely on cost alone is wholly inappropriate – solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the M community implore NICE, the Government & the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patients

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Kind regards

[redacted]

Member of the general public

From: [redacted]
Sent: 14 November 2008 11:30
To: Jeremy Powell
Subject: Petition Regarding The Draft Recommendation on Revlimid

Dear Jeremy

This is my response to the draft recommendation on Revlimid

In response to section 1

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Kind regards

[redacted]

Member of the general public

From: [redacted] [[redacted]]
Sent: 13 November 2008 14:44
To: Jeremy Powell
Subject: Petition Regarding The Draft Recommendation on Revlimid
Dear Jeremy

This is my response to the draft recommendation on Revlimid

In response to section 1

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Kind regards

[redacted]

Member of the general public

From: [redacted] [[redacted]]
Sent: 13 November 2008 11:28
To: Jeremy Powell
Subject: Petition Regarding The Draft Recommendation on Revlimid
Dear Jeremy

This is my response to the draft recommendation on Revlimid

In response to section 1

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Kind regards

[redacted]

Member of the general public

From: [redacted] [[redacted]]
Sent: 13 November 2008 11:46
To: Jeremy Powell

Dear Jeremy

This is my response to the draft recommendation on Revlimid

In response to section 1

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[redacted]

Tel [redacted]

Fax [redacted]

Mobile [redacted]

From: [redacted] [[redacted]]
Sent: 15 November 2008 11:36
To: Jeremy Powell
Cc: [redacted]
Subject: Approval of Revlimid

Dear Mr. Powell,

We presume, you as a NICE personnel are currently in the process of Decision Making about the 'NHS-Prescribability' of this vital drug Revlimid. We also understand that an earlier attempt to get accessability of this drug to Myeloma patients has been thwarted off by NICE, due to it's relative high cost. That decision may have arisen as a result of facts and figures produced at the time from data collected from Drug Economics Vs. Cost Effectiveness etc. However since then more encouraging and reliable data are said to have emerged for serious reconsideration by NICE.

A collective view point from Myeloma Community is that they continue to suffer from this dreadful 'bone-eating' disease with crippling disability. Unfortunately the currently available drugs are too toxic, casing serious side-effects like irriversible kidney and nerve damage, to mention a few. So a new drug is highly welcome in order to minimise suffering and prolong life a little longer. Hence this dire request to the authorities to facilitate achieving our common goal.

It appears that Research and various trials carried out recently in various parts of the world complimented by hands-on experience by various clinicians has shown superiority of this noval drug - Revlimid, compared to the more traditional ones. As such we feel that this opportunity should not be missed and a genuine and discretionary attempt be made to try and include this drug on the NHS formulary of this 'endangered species'.

On a statistical direct comparison with an average drug, the individual annual prescription of Revlimid may appear very high. However Myelomas being such small community, that even if all deserving patients be prescribed Revlimid, the total drug budget will be significantly dwarfed by the cost of Statin preparations or the Diebetic budget. So there are different angles for NICE to look into when searching for the criteria of authorisation. Our next plan is to 'challenge' the manufacturer of Revlimid(CELGENE) to give us a 'Money - Back - Guarantee' for non-responders (if any), as with Valcade.

We now hope that our attempts to put across our points of view for possible inclusion of Revlimid under NICE are convincing to you and all.

Thank you.

[redacted]

From: [redacted] [[redacted]]
Sent: 14 November 2008 22:02
To: Jeremy Powell
Subject: Petition Regarding The Draft Recommendation on Revlimid

' jeremy.powell@nice.org.uk '
Subject: Subject: Petition Regarding The Draft Recommendation on Revlimid
Importance: High

Dear Jeremy

This is my response to the draft recommendation on Revlimid

In response to section 1

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Yours sincerely

[redacted]

(General Public)

From: [redacted] [[redacted]]
Sent: 18 November 2008 12:31
To: Jeremy Powell
Subject: Revlamid

Dear Mr Powell

My husband suffers from multiple myeloma, as did my mother. This is a rare nasty, unpredictable disabilitating disease, but treatment can offer remission periods which greatly improve your life expectancy giving you hope and independence.

We urge you not to reject the introduction of Revlimid on the NHS for suffers of multiple myeloma. This drug is very important in the treatment of this nasty disease. It has proved to be clinically effective, is easy to take in a tablet form and it does not have some of the bad side effects some of the other drugs do have, enabling patients to enjoy a more normal life.

We beg you, please, take all steps to consult the manufacturers on ways which they could reduce costs to make it accessible on the NHS to all patients who need it.

Yours sincerely

[redacted]

From: [redacted] [[redacted]]
Sent: 13 November 2008 20:42
To: Jeremy Powell
Subject: Subject: Petition Regarding The Draft Recommendation on Revlimid

Importance: High

Dear Jeremy

This is my response to the draft recommendation on Revlimid

I would just want to add a personal comment, that my wife has been living with this terrible disease for a number of years and is still relatively young and I am continually unable to comprehend why the right to treatment under the guidance of her consultant should be a postal lottery affair and be linked to both cost and if she is 'clinically exceptional' in the eyes of a group of people whom she has never met. She has worked hard all of her working life. To have the NHS deny her the right to the 'choice' of treatment proven to give a better quality of life for however long the drug may work is indefensable. Both she and I have paid our national insurance stamps all of our working life, as have our parents and our parents parents. It makes a mockery of the right to FREE treatment, whatever the cost and to the ethics of how the NHS was first brought into the world, to give free healthcare to all those citizens born and who have worked all of their lives in the UK.

In response to section 1

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This text wouldn't all quite fit into the online petition which is why I have emailed it.

Kind regards

[redacted]

Husband and carer to my wife who is a patient with MM

From: [redacted]
Sent: 14 November 2008 17:49
To: Jeremy Powell
Cc: [redacted]
Subject: Lenalidomide for the treatment of multiple myeloma - discussion

Hello,
I have obtained your email address from Myeloma UK because I was unable to find anywhere on the NICE site where I could comment on the draft guidance document for use of Lenalidomide for the treatment of multiple myeloma. If I am writing to the wrong person I would be grateful if you would be kind enough to forward this message to the right bit of NICE.

I have just finished reading the draft guidance. As I understand it the guidance accepts that Lenalidomide is effective in prolonging the time to progression of the disease and is more popular with users compared to similar treatrments, but opposes the use of Lenalidomide on the grounds of cost. This is expressed in the guidance in terms of quality-adjusted life year (QALY), and the headline figure is £69,000 per QALY.

The calculation itself is based on the cost of Lenalidomide as being £4368 per 21 capsules of 25mg each. A quick trawl on the internet shows that from anywhere the cost of the drug is no worse than £2435 for this quantity.

This makes a dramatic difference to your QALY calculation and I think you will find it difficult to defend a rejection of an effective treatment when the true QALY is probably nearer £30k at present rates.

I would ask that you reconsider the advice, and at the very least put in realistic prices for the drug.

I am writing to you not as a sufferer of myeloma but as someone who has seen two people dear to me die of the disease and for whom an extra year or two would have been of incalculable benefit.

Regards

[redacted]

From: [redacted] [[redacted]]
Sent: 13 November 2008 15:03
To: Jeremy Powell
Subject: Petition Regarding The Draft Recommendation on Revlimid

Dear Jeremy

This is my response to the draft recommendation on Revlimid

In response to section 1

a.. Revlimid is a clinically effective treatment with impressive data supporting its use in myeloma ('M'). To reject it purely on cost alone is wholly inappropriate – solutions can be found to reduce its cost. Given the nature of the disease and the importance of new developments, the M community implore NICE, the Government & the manufacturer to discuss ways in which the price can be reduced which is acceptable to the NHS and in the best interests of patients

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This text wouldn't all quite fit into the online petition which is why I have emailed it.

Kind regards

[redacted]

A member of the public

From: [redacted] [[redacted]]
Sent: 29 October 2008 11:37
To: Jeremy Powell
Subject: Revlimid (lenalidomide)

Importance: High

Follow Up Flag: Follow up
Flag Status: Red

To say I was disappointed in the recent outcome and statements by NICE which I find insulting regarding Revlimid (lenalidomide) is an understatement.

This is just not good enough.

Here we have a new drug which has been found to have extensive benefits to Multiple Myeloma sufferers which is being denied approval.

I wish to register my utter disgust at NICE.

Yes I am a multiple myeloma sufferer. I am 57 years old and contribute an excessive amount of Tax and N.I. to the coffers of the government and have done since I was 16 years old and I expect, no I demand, that any treatment which is available be funded on the NHS.

Free at point of delivery was what I was told all my life and I expect no less.

[redacted]

[redacted]

Tel: [redacted]
Fax:
Mobile: [redacted]