17 NOV 2008

Andrew Dillon Esq.
Chief Executive
NICE
71 High Holborn
London WC1V 6NA

12th November 2008

Dear Mr Dillon

Re; Draft recommendation on Revlimid (Lenalidomide)

Unfortunately my father suffers from Myeloma. In the past two years, he has been taking an amazing new drug, Revlimid, and now appreciates a normal and fully active life, with no side effects.

There is doubt for him that Revlimid is a wonder drug. It would be dreadful if he were not allowed to take it any longer purely based on cost grounds.

On a personal note, my family is the most important aspect of my life. Your decision on this drug *could potentially have such a bearing on whether he will live or die.*

DEAR SIR,

I UNDERSTAND YOU HAVE REFUGED THE DRUG "REVLIMID" ON THE GROUNDS OF COST.

I AM APPALLED TO THINK YOU JUDGE PEOPLES LIVES ON COST ALONE. I MUST PROTEST TO YOU AND SUGGEST YOU SIT ROUND THE TABLE WITH THE MANUFACTURES OF THIS DRUG AND FIND A SOLUTION

YOURS SINCERELY

13TH November 2008.

Dear Mr. Powell,

I wish to respond most strongly to The Draft Recommendation on Revlimid.

For Section 1

Revlimid is a clinically effective treatment with impressive data supporting its use in Myeloma. 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 Myeloma Community implore NICE, The Government and 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.

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.

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 Myeloma.

The rarity and severity of Myeloma 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, and we urge that any new forms that come out of the consultation will apply to Revlimid.

For section 2

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.

Revlmid is a convenient treatment for patient and their families. Oral dosing does not involve the resource and time-intensive visits to the hospital that is required for the administration of intravenous treatments-patients can self-medicate at home or work.

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.

Newer treatments such as Revlimid can provide substantial benefits to patients in increasing the number of therapeutic options they have available to get back into remission, improving their overall survival and helping them lead an increasingly independent life.

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. However, where the treatment in

question costs thousands of pounds every month, such as Revlimid, the top-up cost 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.

I sincerely hope that NICE will now reconsider its decision in favour of recommending Revlimid.

Yours sincerely,

Respondent Information Form

Your name:	
Your role (pa	
Your address	

Conflict of interest?: *Do you work for, or are projects you work on funded by, the manufacturers of this technology?*

Yes ☐ No ☑ (please tick box)

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☑ Please tick box

13th November 2008.

Response Revlimid consultation

I consider that Revlimid (Lenalidmide) should be made available to all Myeloma patients. For the reason being.

That Myeloma is a rare and severe cancer of the bone Marrow, at present there is no way of dealing with it long-term for patients in the UK.

Revlimid is a licensed and effective drug it's proven to be clinically effective but so far it has been refused to patients by NICE on cost grounds which is torture for all concerned i.e. Families and very close friends and carers. who watch helplessly as the career sufferer only gets worse.

Revlimid is also the first Myeloma treatment where the result between clinical results and side effects is so good that it can be taken for a longer time so they can have a longer life and they will benefit from new drugs in the future.

Revlimid is tablet form and means patients will not need to be admitted to hospital and that means less nursing costs.

PTO

A formula must be found soon by the goverment NICE and the drug companies to price drugs for all the rarer careers which affect relatively few people (4000 in the Uk a year)

Savings must be made by cutting the huge NHS bureaucracy overload.

- The waste of resources should stop, for instance the individual decision making of each seperate PCT. This is also the cause of the divisive and unfair post code lottery of career drug allocation.

So please, please reconsider this proposal. Make this drug available for all who are in desperate need for it so they have a chance of living a longer, more comfortable life.

Jeremy Powell
NICE
Midcity Place
71 High Holborn
London WC1V 6NA

11th Nov. 2080

Dear Sir

As a close friend of a Myeloma patient my response to the Revlimid Consultation is that recent studies are giving new hope to sufferers and have had a positive impact on both their survival and quality of life.

~~The report~~

Revlimid is the first Myeloma treatment to be developed where the balance between clinical effectiveness and side-effects is excellent; it is oral and does not involve costly time-intensive visits to hospital and patients can self-medicate at home or at work.

We need your help to ensure the Government is put into practice the report they have already accepted by Mike Richards, the DoPH of Health's national cancer director calling for

a range of measures to allow patients greater access to life-extending drugs so that top-ups would never have to be paid, financially crippling most families.

He also makes it clear that drug companies need to lower the cost of drugs made available on the NHS and government needs to reconsider its affordability criteria on cancer drugs.

Thank you.

13TH November 2008.

Dear Mr. Powell,

I wish to respond most strongly to The Draft Recommendation on Revlimid.

For Section 1

Revlimid is a clinically effective treatment with impressive data supporting its use in Myeloma. 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 Myeloma Community implore NICE, The Government and 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.

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.

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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.

Newer treatments such as Revlimid can provide substantial benefits to patients in increasing the number of therapeutic options they have available to get back into remission, improving their overall survival and helping them lead an increasingly independent life.

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. However, where the treatment in

question costs thousands of pounds every month, such as Revlimid, the top-up cost 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.

I sincerely hope that NICE will now reconsider its decision in favour of recommending Revlimid.

Yours sincerely,

Respondent Information Form

Your name:	
Your role (patient, carer, family, other):	PATIENT & HUSBAND
Your address:	

Conflict of interest?: *Do you work for, or are projects you work on funded by, the manufacturers of this technology?*

Yes ☐ No ☑ (please tick box)

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☑ Please tick box

-> appraisal team
(Ltr replied on 1/12/08)

14 NOV 2008

RECEIVED
04 DEC 2008

Andrew Dillon Esq.
Chief Executive
NICE
71 High Holborn
London WC1V 6NA

9 November 2008

Dear Mr Dillon

Re; Draft Judgement on Lenalidomide

I am responding to your organisation's appraisal consultation document; I trust that you will excuse my preference for a submission by letter in preference to completing boxes online for such a crucial subject.

Introductory remarks

My submission is primarily as a Fellow of the Institute of Actuaries. For those in your organisation who are not familiar with my profession, our field of expertise combines mathematics and statistics with economics and finance.

It is also a fact that I am a myeloma case, having undergone a stem cell transplant, taken thalidomide (unable to tolerate) and I have been on lenalidomide for the past two years (during which time I have gained my private pilot's licence)! During the past two years, I have been able to lead a 100% normal lifestyle. The cost of my medication is currently met by my medical expenses insurer, but only on a temporary basis. Furthermore, as you can see from my address, I am not directly affected by your decisions.

Also, although I do not possess any medical qualifications, since inception in 1995, I have been and I am an Honorary Fellow of the Medical Defence Union; hence I am well aware of medical litigation and its impact on all parties concerned.

Your consultation document; key points

Clinical trials generally (and those utilised in your draft judgement) suffer certain fundamental weaknesses:-

- The nature of the sample. It is self evident that many new entrants are already in poor condition, especially with myeloma which until very recently lacked any convincing solutions. The effect of this can be to significantly drag down the median.

- The size of the sample. In my profession, we would be concerned as to the robustness of conclusions drawn from such small samples despite the statistical tests stated. This problem is exacerbated by the stratification as exemplified by section 3.2 where there are a considerable number of sub groups.

- The short duration of the trials. Allowing for the staggered nature of new entrants (which is clearly unavoidable), a period of say less than five years is again a further substantial restraint on the statistics

- Above all, the use of the median is a very crude tool. Taking all of my points together, what is evident is how little is known about the ultimate expectation of life for the lucky 50% who exceed the median. In the case of a very successful drug, the absence of this information is absolutely crucial.

Despite all these handicaps, the trials show convincingly that lenalidomide (Revlimid) is a very successful drug and I am convinced that, in the future, those on the right side of the median will have enjoyed many extra years of life.

Elsewhere, you have attempted some curve trend fitting to derive a mean instead of the median. For the reasons I have covered, your estimates look to be far too pessimistic.

Other points

The above are my key points as an actuary. My other points are:-

- In section 4, you try to make an economic case by a comparison with Velcade (I'm sure the irony of your initial rejection of Velcade is not lost on anyone!). I have no doubt that the expert practitioners will say that Velcade is only suited to particular circumstances, but my point is that Velcade is an unpleasant drug that imposes serious restrictions on lifestyle whilst lenalidomide can be managed to be completely without complications. I should add that I am the accredited patient reviewer for the Myeloma UK booklet on Revlimid.

- Have you considered that significantly enhanced usage of lenalidomide following a positive decision from NICE could lead to very realistic downward pressure on the price?

In conclusion, there is no doubt that, for many, lenalidomide is a life saving wonder drug. All other options to date have serious drawbacks. However, the current cost is beyond the financial means of virtually every potential beneficiary of lenalidomide.

Therefore, I do not envy your role in potentially rejecting it for the NHS solely on cost grounds, thereby aiding the UK government in a euthanasia programme.

Yours Sincerely

RESPONSE TO DRAFT RECOMMENDATIONS ON REVLIMID.

FROM -

PATIENT

ENGLAND

Section 1 - Revlimid is a licensed and clinically proven drug for the effective treatment of Myeloma. The disease is one of the rare cancers, which in the past has suffered from insufficient research by the scientific community. Now that resources are at last being devoted to it, the fact that each encouraging ray of light is immediately stamped upon on the basis of cost is grossly unfair. It is almost as if the authorities feel it a bounden duty to reject any development, before embarking upon a battle of wills that invariably attracts bad publicity, and eventually a climb down. It would surely be more beneficial to all concerned to adopt a more rational approach.

It should also be appreciated by those who sit in judgement - the vast majority presumably in good health - that their pronouncements, always heralded in a blaze of publicity, create pressure on patients that is sometime difficult to bear. HAVING SURVIVED THE PROLONGED NEGOTIATIONS TO OBTAIN VELCADE, I HAVE NO WISH TO BE SUBJECTED TO THE SAME STRESS OVER THE SUPPLY OF REVLIMID.

The question of the drug's availability is an incongruity which requires addressing urgently. Allocation under the exceptional case policy is a postcode lottery and more specific and rational guidelines are needed.

The recent case of Ross -v- West Sussex PCT draws attention to the myopic and insular attitude adopted by most government agencies over the allocation of financial resources. I am reliably informed that this case cost in the region of £100,000.00 - approximately quadruple the minimum figure quoted by NICE for allowing a properly prescribed treatment in the first instance. As sure as night follows day, there will be many more such cases, unless urgent discussions take place between NICE, the Dept of Health and the drug company, leading to reduction in costs and enabling a swift resolution.

Section 2 - Revlimid brings with it other significant physical benefits and financial savings which, in my reading of the NICE document, are conveniently minimised. It can be self-administered orally within the comfort of the patient's home, thus obviating the expense of staff and equipment necessary for other intravenously introduced drugs. The severity of side effects is significantly reduced, making longer term treatment possible, and also reducing the costs accrued by necessary medical intervention to treat those complications, some involving months of therapy and a multi-discipline approach.

Myeloma patients must be offered a range of suitable drugs to establish which will allow them to take advantage of a longer life in some comfort and hope

It would be spurious for any politician or official to suggest that the recent pronouncement on 'top-up' fees will be of benefit to the majority of people requiring sophisticated drug therapy. If those who cannot afford to pay for their treatment are denied there will be a public outcry the like of which can only be imagined.

To - Jeremy Powell
NICE
MidCity Place
71 High Holborn
LONDON WC1V 6NA

STEPHEN HAMMOND MP

HOUSE OF COMMONS

LONDON SW1A 0AA

Prof David Barnett
Chairman
National Institute for Health and Clinical Excellence
MidCity Place
71 High Holborn
LONDON WC1V 6NA

12 November 2008

Dear Prof Barnett

DRAFT RECOMMENDATION ON REVLIMID

I am writing on behalf of my constituent, , who suffers from Myeloma, and is currently receiving Revlimid which for the time being is being funded by his insurers. I am aware that this is an extremely expensive drug.

I understand that responses to the consultation need to be with NICE by 18 November. I know personally and know that the use of Revlimid has made a huge difference to the management of condition and I do hope that NICE will look favourably at the points put forward by Myeloma UK in respect of this drug.

Many thanks.

Yours sincerely

Steph

Dear Mr. Powell,

I wish to respond most strongly to The Draft Recommendation on Revlimid.

For Section 1

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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.

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 Myeloma.

The rarity and severity of Myeloma 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, and we urge that any new forms that come out of the consultation will apply to Revlimid.

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Newer treatments such as Revlimid can provide substantial benefits to patients in increasing the number of therapeutic options they have available to get back into remission, improving their overall survival and helping them lead an increasingly independent life.

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. However, where the treatment in

question costs thousands of pounds every month, such as Revlimid, the top-up cost 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.

I sincerely hope that NICE will now reconsider its decision in favour of recommending Revlimid.

Yours sincerely,

Respondent Information Form

Your name:	
Your role (patient, carer, family, other):	DAUGHTER
Your address:	

Conflict of interest?: *Do you work for, or are projects you work on funded by, the manufacturers of this technology?*

Yes ☐ No ☑ (please tick box)

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13TH November 2008.

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I sincerely hope that NICE will now reconsider its decision in favour of recommending Revlimid.

Respondent Information Form

Your name:	
Your role (patient, carer, family, other):	DAUGHTER.
Your address:	

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Yes ☐ No ☑ (please tick box)

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☑ Please tick box

7 Nov 08

Dear Sir,

I am writing to voice my very strong opinion that Revlimid should be available to all the patients who so desperately need it.

No body can be expected to pay thousands every month if the NHS cannot provide it and I urge you and everybody involved to reconsider helping the relatively few people who need Revlimid. The quality of life for her and her carers cannot and must not come

down to money particularly when there is a vast amount of wastage in the NHS.

Please, please, please make this drug available for all who are suffering.

Yours faithfully,

Dr Tony Wright MP Cannock Chase

HOUSE OF COMMONS

13 December 2008

David Barnett
Chair, Appraisal Committee
(Multiple myeloma – lenalidomide)
National Institute for Health and Clinical Excellence
MidCity Place
71 High Holborn
London, WC1V 6NA

Dear Mr Barnett,

I am writing in response to a letter from my constituent, , regarding NICE's recent draft recommendation on Revlimid (lenalidomide) for the treatment of multiple myeloma. Please find a copy of his letter enclosed.

I understand that the initial meeting of the appraisal committee concluded that lenalidomide should not be made available to myeloma patients on the NHS, as it was not considered to be a cost-effective use of NHS resources.

I am aware that you had called for comments in advance of your second committee feeling in the New Year. Owing to the relatively short time window during which these comments were to be received I hope you will accept this letter as an expression of my constituents concern with the decision reached thus far.

I write to express call for NICE to work with the Department of Health and the drug manufacturer Celgane to make this treatment better value for money.

I would be grateful for your response on this issue.

From:

Sent: 18 November 2008 20:54

To: WRIGHT, Tony

Subject: Request for help for Myeloma patients.

Importance: High

Dr Tony Wright MP
House of Commons,
London.
SW1A 0AA

Dear Mr. Wright,

Re: Draft recommendation on Revlimid (lenalidomide) for treatment of myeloma

I am writing to you as a constituent whose son in laws father is suffering from myeloma to seek your support in an issue of great importance.

On 28 October NICE issued its draft recommendation that **Revlimid should not be made available to myeloma patients on the NHS**. It has decided that it is *"not cost-effective"* even though it agreed that the clinical evidence was strong.

This is the second time that myeloma patients have been in this situation. You may remember the struggle faced in getting access to Velcade on the NHS. Velcade was also rejected by NICE due to cost. It was later approved after many months of tireless campaigning and a price reduction scheme was proposed by the manufacturer. During this time, however, many suitable patients did not get the chance to try Velcade.

Patients do not want to have to go through this long drawn-out process again. Myeloma patients are already experiencing difficulty in accessing Revlimid through local decision-making processes. We must get a positive final decision from NICE, due in January 2009, to ensure patients do get access to Revlimid.

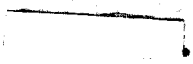
Recent studies have shown that the introduction of novel treatments over the last decade such as Velcade and Revlimid has had a positive impact on both the survival and quality of life of myeloma patients.

To a myeloma patient, Revlimid will offer a treatment that is oral, easy to use, does not give awful side-effects and lets patients get on with their life with minimal disruption.

Your help is needed to urge the Department of Health, NICE and the manufacturer (Celgene) to agree how to make this treatment better value for money for the NHS. The Department of Health has already said it wants to use more cost reduction schemes. The myeloma community now needs the Department to put this into practice.

Please can you represent my concerns to the Department of Health, NICE and Celgene to ensure that this situation is resolved?

Yours sincerely



03/12/2020

Mr [illegible] Powell,
NICE,
Midcity Place,
71, High Holborn.
London. WC1V 6NA.

14th November 2008

Dear Mr Powell,

I am writing in response to the draft recommendation on Revlomid in the treatment of myloma.

Re Section 1.

Revlomid is known to be clinically effective in the treatment of myeloma and as such should not be

rejected because of the cost. All efforts should be made to reduce the cost by the manufacturer and the Government so that it will be acceptable to the NHS.

Patients with myeloma find the condition very difficult to cope with especially when they know that there is an effective treatment which they are unable to have because of the cost. A failure by NICE to reconsider its draft will make it very difficult for patients to get this important treatment.

Re Section 2. Revlomid has few side

effects and so patients can remain on the drug for a longer period of time. Because it is administered orally it will avoid a great deal of inconvenience and length of time because it does not have to be administered intravenously.

Finally I would ask NICE to reconsider its draft in the interest of the patients.