# Esther McVey

*Member of Parliament for Wirral West*


Sir Andrew Dillon
Chief Executive
National Institute for Health and Clinical Excellence
MidCity Place
71 High Holborn
London
WC1V 6NA

24 OCT 2011

20th October 2011

Dear Sir Andrew

**Yervoy (Ipilimumab)**

I have been contacted by my constituent, [redacted] regarding NICE's decision over Yervoy (Ipilimumab). Please find enclosed a copy of her letter.

Please could I ask that you give full consideration to approving Yervoy to make it available to patients fighting melanoma based on an evidence-based approach and in view of the points raised by my constituent.

I look forward to your comments.

Yours sincerely

**Esther McVey MP**
Encl.


The Parade, Hoylake Community Centre, Hoyle Road, Hoylake Wirral CH47 3AG
Telephone: 0151 632 4348 Email: officeofesthermcveymp@parliament.uk
Web: www.esthermcvey.com http:/twitter.com/esthermcveymp

[redacted]

14 October 2011

Miss Esther McVey MP
House of Commons
London
SW1A 0AA

Dear Miss McVey

**NICE's Decision on Yervoy (Ipilimumab)**

I am writing to you as a constituent and stage 3 melanoma patient, to express my extreme disappointment at NICE's decision to deny UK melanoma patients access to Yervoy and to ask that you make representations to NICE on my behalf in order to ensure that this drug is approved when reviewed in November.

I was first diagnosed with melanoma 15 years ago, and foolishly believed that following surgery to remove it, I was clear of the disease. 10 years later, the melanoma recurred and I had further extensive surgery to remove it. Another year later, and I was praying that the golf ball sized lump that appeared almost overnight in my groin was anything but melanoma. My prayers were not answered and I had to endure further surgery to remove the lymph nodes from my groin and pelvis.

For the past four years, I have been living with this sword of Damocles over my head, knowing that my own immune system is the only defence I have against melanoma returning and undoubtedly proving fatal.

Yervoy is the first drug to be licensed in the UK that demonstrates an overall survival benefit for people with advanced melanoma and it has the backing of clinicians and patient groups worldwide. If it's not available on the NHS, patients such as I, will continue to have limited treatment options beyond the current standard of treatment that was first licensed in the 1970s and which had had very little success then and has very little success now.

You may not be aware that rates of malignant melanoma in the UK are growing faster than any other cancer, and as many people will die from melanoma each year in the UK as will be diagnosed with cervical cancer. Melanoma isn't self inflicted, it doesn't just affect "tanorexics", it affects men, women and children regardless and it isn't "just" skin cancer.

Please help me.

Yours sincerely,

[redacted]

cc Professor Sir Mike Rawlins (NICE), Andrew Lansley (MP)

31/10/2011

[redacted]

- 2 NOV 2011

Dear Professor Rawlins,

I wish to express my disappointment at the recent decision by the National Institute for Clinical Health and Excellence (NICE) to deny access to the drug Ipilimumab for sufferers of advanced melanoma. I am aware that this board has jurisdiction over drug availability in England and Wales, and have great concern that this may be followed by a similar decision in Scotland by the Scottish Medicines Consortium.

I find the decision NICE has made regarding Ipilimumab appalling. There have been no effective treatments for melanoma until now. This is the first treatment for this condition which demonstrates overall survival benefit. 30% of people treated with Ipilimumab will experience an improvement in median survival, and 10% of people will have long-term benefits. It should be the gold standard in advanced melanoma treatment. I believe NICE have not fully acknowledged that melanoma predominantly affects young people who work and raise families and contribute greatly to the economy. There not been a direct cost comparison to current melanoma treatment. Ipilimumab is a landmark drug which will greatly affect the quality of lives of a small number of people. I feel it is unethical to withhold a treatment which is genuinely life extending.. NICE have made a decision which is devastating and incomprehensible to those who suffer from cancer and their carers.

NICE have commented on the cost effectiveness of this drug. New drugs are always expensive. Competition, widespread and longterm use will lower costs. A national procurement contract would remove cost variations and ensure a better price. Ipilimumab has met the criteria for being a life-extending, end-of-life treatment. The trial evidence presented for this consideration was robust. The NICE committee is fully in agreement on this. Approximately 400–500 people with advanced melanoma progress onto second-line treatment each year in the UK. Although costs per patient are high it is restricted to a very small group of people. It has been over 30 years for a breakthrough in melanoma treatment. I believe this timespan partly explains the costs and makes them justifiable

While waiting on guidance from NICE treatment should be available nationally. It is unethical that Ipilimumab is currently available in some areas of England due to The Cancer Drugs Fund which does not even exist in Scotland.

It has been a 30 year wait for any breakthrough in the treatment of melanoma. Ipilimumab is a landmark drug. It is entirely unacceptable that patients and families

While waiting on guidance from NICE treatment should be available nationally. It is unethical that Ipilimumab is currently available in some areas of England due to The Cancer Drugs Fund which does not even exist in Scotland.

It has been a 30 year wait for any breakthrough in the treatment of melanoma. Ipilimumab is a landmark drug. It is entirely unacceptable that patients and families should have to wait another 3 years for this to be reconsidered particularly considering its use in some areas of England. I believe this treatment should be available nationally and urge you to ensure that we allow access to this drug to give real hope to melanoma sufferers and their families. If this drug is not available on the NHS patients with advanced melanoma will have limited treatment options beyond those which were introduced in the 1970s.

I look forward to hearing your response and am grateful for your help in ensuring the availability of this landmark treatment for melanoma patients.

Yours sincerely

While waiting on guidance from NICE treatment should be available nationally. It is unethical that Ipilimumab is currently available in some areas of England due to The Cancer Drugs Fund which does not even exist in Scotland.

It has been a 30 year wait for any breakthrough in the treatment of melanoma. Ipilimumab is a landmark drug. It is entirely unacceptable that patients and families should have to wait another 3 years for this to be reconsidered particularly considering its use in some areas of England. I believe this treatment should be available nationally and urge you to ensure that we allow access to this drug to give real hope to melanoma sufferers and their families. If this drug is not available on the NHS patients with advanced melanoma will have limited treatment options beyond those which were introduced in the 1970s.

I look forward to hearing your response and am grateful for your help in ensuring the availability of this landmark treatment for melanoma patients.

Yours sincerely

JOHN GLEN M.P.

HOUSE OF COMMONS
LONDON SW1A 0AA
*john.glen.mp@parliament.uk*
*www.johnglenmp.com*

JG/SH/Cons/[redacted]

31 OCT 2011

Sir Andrew Dillon
Chief Executive
National Institute for Health and Clinical Excellence
MidCity Place
71 High Holborn
London
WC1V 6NA

25th October 2011

Dear Sir Andrew,

I enclose correspondence from my constituent, [redacted] who is suffering from melanoma.

It is a persuasive and moving letter in which [redacted] details his own experiences of cancer and makes specific reference to the decision taken by NICE not to make Ipilimumab available via the NHS.

I do realise that the drug comes at a significant cost and that at present the committee's position – based on the evidence to date – is that the drug cannot be considered a cost effective use of NHS resources.

However, this is currently open to consultation and that feedback received during this will inform the next draft guidance to be issued.

There is growing awareness of the increase of melanoma. In the last week I have been asked to two parliamentary briefings on the subject; the first is in direct response to the decision taken by NICE not to make Ipilimumab available on the NHS.

There are genuine concerns about access to the drug given that the incidence of Melanoma is on the rise, and that it is the second most common cancer in the 15-34 age group.

I do understand that the longer term efficacy of the drug has yet to be proven and that this is a cost v. benefit decision. But there are those for whom it might be a lifeline or at least an extension. To know the drug exists, and that it has worked for some (albeit a small number) and yet will remain inaccessible to them is devastating.

Constituency Office 12 Brown Street, Salisbury, SP1 1HE
Telephone: 01722 323050 Fax: 01722 327080

You make reference to the possibility of the manufacturer reducing the acquisition cost to the NHS through a patient access scheme and I wonder how viable this might be?

I should welcome any indication as to the likelihood that NICE will reconsider the availability of the drug so as to make it more accessible for those suffering from advanced melanoma.

With best regards

John

**John Glen MP**
**Member of Parliament for Salisbury**

[redacted]

Professor Sir Mike Rawlins
Chair
NICE
Mid City Place
71 High Holborn
London
WC1V 6NA

18 OCT 2011

14 October 2011

Dear Sir

Please find enclosed a letter sent to my local MP, John Glen.

Yours Faifthfully.

[redacted]

John Glen MP
Morrison Hall
12 Brown Street
Salisbury
SP1 1HE

14 October 2011

Dear Mr Glen

As a constituent of yours I am hoping that you will be able to make representation on my behalf to the National Institute for Health and Clinical Excellence (NICE). They have reviewed a new drug called Yervoy (also known as Ipilimumab) for inclusion as a NHS treatment for Malignant Melanoma but today announced that it will not be made available as a standard treatment.

As I understand it, this decision has been made on a cost v benefit basis and whilst I understand that the NHS doesn't have infinite resources, the decision is devastating to those who are suffering from this particularly nasty and misunderstood cancer. I would ask you to carefully consider the following question; what price a life?

Without entering into great detail, until recently, the only way to control melanoma has been to cut it out. This has meant that if it metastasises to the brain or other major organ, which invariably it does, there has been little the medical profession could do, other than offer palliative care. Melanoma does not respond to either chemotherapy or radiotherapy, although both are employed at times as part of a palliative care regime – a regime incidentally which was implemented in the early 1970's and has remained pretty much unchanged since then.

Yervoy has been the first real breakthrough in treatment for Melanoma in three decades and offers great hope to sufferers. Whilst it is not successful in all cases, it has been proven to demonstrably prolong life in many and in a few, has been a cure. It has the backing of a number of clinicians and patient groups and as such was licensed for use in the UK. For it now to be turned down on the grounds of cost in England & Wales is desperately disappointing.

As you will probably have gathered by now I am a melanoma sufferer. I had a lump removed from my shoulder in April of this year, which initially was assumed to be a squamous cell carcinoma. Upon further investigation it was found to be a melanoma which had spread to the lymph nodes under my left arm pit. I was taken into Hospital and had a large portion of my shoulder removed, as well as an axillary clearance from under my armpit.

Having volunteered for any clinical trials that were appropriate to my condition, I was accepted onto one called MAGE-A3 being conducted by GSK. As part of the trial I had to undergo a CT scan and the results of

this revealed that the disease had spread to the lymph nodes in my neck. Consequently I was back in for surgery and had 71 lymph nodes removed from the left hand side of my neck about four weeks ago.

I am a massively positive person and determined not to let melanoma take over my life. As such I have continued at work, still manage [redacted] Football Club and carry on pretty much as I did before diagnosis. I won't lie, it has been a terrific strain on those nearest and dearest to me but they too remain positive on my behalf and I am surrounded by the most fantastic friends and family. All of that said, my prognosis is not good and I know that one day I will die as a result of melanoma. As it stands I do not need it this very instant but I undoubtedly will, therefore Yervoy (or something similar) gives me hope that my days are nowhere near as numbered as they could be – NICE are trying to take that hope away.

Having signed up and done my bit for crown and country (17 years in the Army) it would be nice if I wasn't abandoned by the same country at my hour of need. Ironically, it is most likely that service which is responsible for my melanoma. As somebody who has always been paranoid about the sun and the damage it can do, the only real exposure I have ever had to it was during my time in the desert for the first Gulf War (1991). At the ripe old age of 50 I am not ready to throw the towel in just yet, I have far too much to offer life and it me, so I ask again; what price a life?

It is my understanding that having made their initial decision, NICE now open a small consultation window for all interested parties to contact them. This closes on the 4th of November, so time is of the essence and to that end I urge you to contact them expressing support of Yervoy as a treatment for melanoma.

Thank you for taking the time to read this and thank you in anticipation of your kind and prompt help. I look forward to hearing from you.

Yours Sincerely

[redacted]

cc. Professor Mike Rawlings, NICE

Andrew Lansley MP, Secretary of State for Health.

Professor Sir Mike Rawlins
Chairman
National Institute for Health and Clinical Excellence
MidCity Place
71 High Holborn
London
WC1V 6NA

[redacted]

31/10/2011

- 7 NOV 2011

Professor Rawlins

I wish to express my disappointment at the recent decision by the National Institute for Clinical Health and Excellence (NICE) to deny access to the drug Ipilimumab for sufferers of advanced melanoma. I am aware that this board has jurisdiction over drug availability in England and Wales, and have great concern that this may be followed by a similar decision in Scotland by the Scottish Medicines Consortium.

As a healthcare professional caring for patients with cancer and as a daughter whose father has metastatic melanoma I find the decision NICE has made regarding Ipilimumab appalling. There have been no effective treatments for melanoma until now. This is the first treatment for this condition which demonstrates overall survival benefit. 30% of people treated with Ipilimumab will experience an improvement in median survival, and 10% of people will have long-term benefits. It should be the gold standard in advanced melanoma treatment. I believe NICE have not fully acknowledged that melanoma predominantly affects young people who work and raise families and contribute greatly to the economy. There not been a direct cost comparison to current melanoma treatment. Ipilimumab is a landmark drug which will greatly affect the quality of lives of a small number of people. As a doctor I feel it is unethical to withhold a treatment which is genuinely life extending.. NICE have made a decision which is devastating and incomprehensible to our family and those who suffer from cancer and their carers.

NICE have commented on the cost effectiveness of this drug. New drugs are always expensive. Competition, widespread and longterm use will lower costs. A national procurement contract would remove cost variations and ensure a better price. Ipilimumab has met the criteria for being a life-extending, end-of-life treatment. The trial evidence presented for this consideration was robust. The NICE committee is fully in agreement on this. Approximately 400–500 people with advanced melanoma progress onto second-line treatment each year in the UK. Although costs per patient are high it is restricted to a very small group of people. It has been over 30 years for a breakthrough in melanoma treatment. I believe this timespan partly explains the costs and makes them justifiable

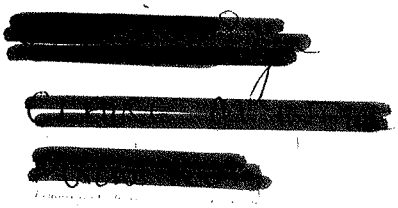
While waiting on guidance from NICE treatment should be available nationally. It is unethical that Ipilimumab is currently available in some areas of England due to The Cancer Drugs Fund which does not even exist in Scotland.

It has been a 30 year wait for any breakthrough in the treatment of melanoma. Ipilimumab is a landmark drug. It is entirely unacceptable that patients and families

should have to wait another 3 years for this to be reconsidered particularly considering its use in some areas of England. I believe this treatment should be available nationally and urge you to ensure that we allow access to this drug to give real hope to melanoma sufferers and their families. If this drug is not available on the NHS patients with advanced melanoma will have limited treatment options beyond those which were introduced in the 1970s.

I look forward to hearing your response and am grateful for your help in ensuring the availability of this landmark treatment for melanoma patients.

Yours sincerely



[redacted]

- 1 NOV 2011

To Nice Appraisal Committee,

I am writing to you to ask you to reconsider your decision not to approve the cancer drug Ipilimumab.It is a drug that has given hope and solace to me and my family at a terrible time. My husband [redacted] was diagnosed with stage 4 melanoma 15 months ago. At the time of his diagnosis we were told he had between 6 and 9 months to live. As you can imagine we, as a family, were absolutely devastated. There are no words to express the sadness we felt. One of the things which tortured me the most was the effect it would have on our two teenage daughters. They were at a stage in their lives where every moment with their Dad was vital. My eldest was soon to be sitting her GCSE's and both girls struggled to come to terms with the fact that their dad would be taken from them so soon, before they had time to come to terms with the inevitable, Luckily [redacted] was prescribed Ipilimumab at the outset and 15 months on he is still with us and relatively well. He was there for their birthdays and for the school leaving prom. He was there to encourage and reassure our daughter as she sat her exams. We hope and pray that he will be here for one more Christmas. We truly believe that it is the drug Ipilimumab that is the reason he is still with us enjoying the quality of life he still has, against all the predictions the doctors made. To us and to many other families like us the drug is priceless. Without general approval of this drug, thousands of people will be robbed of the chance to spend significantly longer with those that they love.

Yours sincerely,

[redacted]

COPY OF LETTER SENT TO MY MP

[redacted]

25 OCT 2011

24 October, 2011

Dear Dr Poulter

RE: Decision of NICE to deny making the drug Yervoy available

I have a friend with advanced melanoma and the drug Yervoy (Ipilimumab) has shown promising results as a treatment for the disease and is backed by a number of clinicians and patient groups. It has been denied by NICE but the case will be reviewed in November. I would ask you to make representations on behalf of melanoma sufferers to ensure that the drug is approved following the review.

My friend is a young woman of 30 who has 4 small boys, and she is desperate for any treatment that will prolong her life so that her sons will at least remember her. Yervoy is the first new and effective treatment for melanoma since the 1970s and is regarded by experts in the field as a breakthrough. The case for making it available is considerable and I therefore hope you will able to lend your support to the campaign.

A copy of this letter has also been sent to Professor Sir Mike Rawlins, Chair of NICE and Rt Hon Andrew Lansley CBE MP, Secretary of State for Health.

Yours sincerely

[redacted]

[redacted]

27th October 2011

Professor Sir Mike Rawlins
Chair
NICE
Mid City Place
71 High Holborn
London
WC1V 6NA

- 2 NOV 2011

Dear Professor Rawlins,

I have enclosed in this an envelope & letter I sent to my local MP Karen Lumley regarding the recent decision by NICE to refuse the melanoma drug Ipilimumab on the NHS due to cost.

I hope that you will also read this letter and reconsider this judgement on the 4th November.

I look forward to hearing from you.
With best regards,

[redacted], Student, 19 years old.

[redacted]

Karen Lumley MP
House of Commons
London
SW1A 0AA

Dear Ms. Lumley,

I am writing because I feel that you will be able to help. I am at university currently, but I am from [redacted]. My mother has Melanoma, and has been in and out of hospital constantly since 2008 due to reoccurring tumours. She has had countless operations and consultations to removed recurring malignant tumours, and I must say that it is extremely upsetting to find out that Yervoy (Ipilimumab) has so far been declined by NICE. This is a shocking decision as clinicians and patients have been waiting for three decades for a treatment breakthrough in advanced melanoma. My mother would be someone who would greatly benefit from this treatment.

I would like to ask you to make representations to NICE on my behalf in order to ensure that Yervoy (Ipilimumab) is approved when NICE review it in November this year.

It was said by NICE that the reason for rejecting this breakthrough drug was not on grounds of effectiveness, but because of the price. I can understand the NHS is under a great amount of stress right now, however I would ask what costs more, the £19,000 for a drug which would not only work, but also leave the patient considerably more comfortable (the latest operation my mother had to undergo involved a skin graft onto her back. Two weeks after this operation she had to have the staples (not stitches) removed without any kind of local anaesthetic. Ipilimumab also has side effects, however these pale in comparison to the kind of pain and discomfort someone has to endure with the amount of operations and scans someone like my mother has had to endure.

We all know how horrible cancer can be, I lost my Grandmother to bowel cancer only 4 weeks ago., and 12 years ago my other Grandma to breast cancer. Cancer is one of the biggest killers in the UK, and I do not understand how NICE can dismiss this drug purely on financial grounds if it such a breakthrough in cancer treatment. I understand that Yervoy has the backing of a number of clinicians and patient groups and it is the first treatment to be licensed in the UK which demonstrates an overall survival benefit for people with advanced melanoma (like my mother). If this drug is not available on the NHS, patients will continue to have limited treatment options beyond the current standard of care that was first licensed in the 1970s.

In addition I would like to highlight the growing incidence of melanoma. For example, over the last 25 years, the rate of malignant melanoma in the UK has risen faster than any of the top 10 cancers in the UK and kills over 2000 people in the UK each year, with an average 22 years of more life lost from each melanoma death than many other cancer.

I will also be copying this letter to the Secretary of State and to the Chair of NICE.
I look forward to hearing from you.

Best regards,

[redacted]

[redacted]

20th October 2011

Adam Afriyie MP
House of Commons
London
SW1A 0AA

26 OCT 2011

Dear Mr Afriyie

I am writing to you as a constituent and a melanoma cancer patient, to ask that you make representations to NICE on my behalf in order to ensure that Yervoy (Ipimumab) is approved when NICE review it in November.

I am disappointed to hear that Yervoy has so far been declined by NICE. This is a shocking decision as clinicians and patients have been waiting for three decades for a treatment breakthrough in advanced melanoma.

I was diagnosed with advanced Melanoma in January of this year and am terminally ill. I am 39 years old with two young children, [redacted] is 6 years old and [redacted] is just 17 months old. In short this drug could enhance my survival significantly in the future, so that my boys have a Mummy for as long as possible. My disease is currently stable and I am still very fit and active, as you have to be with young children. I also work 3 days a week, contributing to this countries economy and to the NHS, just as I have done since leaving education. It's shocking to me that when I need something that I've been contributing towards all my adult life, the drugs won't be there for me when I need them.

I understand that Yervoy has the backing of a number of clinicians and patient groups. It is the first treatment to be licensed in the UK which demonstrates an overall survival benefit for people with advanced melanoma. If this drug is not available on the NHS, patients like me will continue to have limited treatment options beyond the current standard of care that was first licensed in the 1970s.

There is a growing incidence rate of melanoma. For example, over the last 25 years, the rate of malignant melanoma in the UK has risen faster than any of the top 10 cancers in the UK. Malignant melanoma kills over 2000 people in the UK each year, with an average 22 years of more life lost from each melanoma death than most other cancers.

I am copying this letter to the Secretary of State and the Chair of NICE.

I look forward to hearing from you.

Yours sincerely,

[redacted]

cc Professor Sir Mike Rawlins, NICE and Andrew Lansley MP, Secretary of State for Health

RE appeal against
decision not to approve
Yervoy for NHS use.

[redacted]

Oct 15th 2011

18 OCT 2011

Dear Sir Rawlins,

Before 2008 I had heard of malignant melanoma but it wasn't until then it became a subject of my first and last thoughts everyday.

My 12 year old son was diagnosed in early January 2009 after a very odd mole was removed in December 2008. By 2010 it was in his lungs.

I then learned about the limited treatment options, the way sufferers searched and competed for places in drug trials sometimes going abroad and sometimes finding they had got a place on a trial and then finding they were on the placebo or observation arm of the trial. It came as a shock to realise to a child of 13 there were no options AT ALL.

Suddenly after years of no progress earlier this year 2 drugs were licensed for use and this was greeted with enthusiasm from sufferers & their families. This hope was dashed yesterday when

NICE failed to approve Yervoy for use by the N.H.S. This is the only drug which has the potential to prolong the lives of all sufferers. The other Vemurafenib is a Braf inhibitor which requires a genetic mutation in order to be of any use which less than 50% sufferers show.

As [redacted] my son was not eligible for trials we had to write and beg for drug companies to give unlicensed drugs to him on compassionate grounds.

I had hoped that when 2 drugs were licensed it would mean no family would ever have to go through what we did to find a treatment. However I feel that if funding is not available for this drug the situation will actually get worse particularly for a child who can't search for a trial (not that I believe any sick person should be put in the position of hunting down their own best treatment. That is why people fall prey to weird and wonderful diets and expensive worthless drugs in desperation).

As I am sure you know although melanoma is unusual in a child of 12 but by no means rare and becoming less unusual.

We have been "lucky" in that Bristol Myers did provide us with a course of Yervoy which held his tumours back long enough to secure our next step. Glaxo Smith Kline provided us with a Braf inhibitor similar to vemurafenib (Roche turned us away). Almost 2 years after being diagnosed with stage 4 melanoma our Son is still attending School. He suffered no side effects from either drug and the time these drugs have bought us has been good quality time. He has been able to holiday and we have all built up extra memories.

As a mother with a terminally ill child I derive comfort from knowing that everything that could be done was done. To be left with 'What Ifs' is so cruel. I don't believe I am any different from a wife losing her husband a child losing a parent etc etc.

You can see why for me it is so important to ask you to rethink this decision.

Thank you for reading.

[redacted]

[redacted]

21 October 2011

House of Commons

London SW1A 0AA

27 OCT 2011

Dear Dr Wollaston

As one of your constituents and a carer for my wife who is being treated for advanced melanoma I am writing to you requesting that make representations to NICE on our behalf in order to ensure that Yervoy (Ipilimumab) is approved when they come to review it in November.

I am disappointed to hear that Yervoy has so far been declined by NICE. This is a shocking decision as clinicians and patients have been waiting for three decades for a treatment breakthrough in advanced melanoma.

My wife is currently undergoing chemotherapy for advanced melanoma and whilst there was only a 20% chance of the chemotherapy taking effect she has been fortunate to receive a partial response. However we understand that this is only likely to have a temporary effect and will need to be followed up with one of the more advanced drugs eg. Yervoy or a BRAF inhibitor drug (yet to be licensed).

From the research that is available, Yervoy is the first treatment to be licensed in the UK which demonstrates an overall survival benefit for people with advanced melanoma and has the backing of a number of clinicians and patient groups.

If this drug is not available on the NHS then patients will continue to have limited treatment options beyond the current standard of care that was first licensed in the 1970s.

It is also worth pointing out that over the past 25 years, the rate of malignant melanoma in the UK has risen faster than any of the top 10 cancers in the UK, this disease kills over 2000 people in the UK each year, with an average 22 years of more life lost from each melanoma death than many other cancers.

I am sending a copy of this letter to the Secretary of State and the Chair of NICE and look forward to receiving your reply.

Yours sincerely

[redacted]

Cc: Professor Sir Mike Rawlins, NICE and Andrew Lansley MP, Secretary of State for Health

Peter Luff MP
Mid Worcestershire

HOUSE OF COMMONS
LONDON SW1A 0AA

31 OCT 2011

Sir Andrew Dillon
Chief Executive
National Institute for Health and Clinical Excellence
MidCity Place
71 High Holborn
London
WC1V 6NA

26th October 2011

Dear Sir Andrew,

[redacted]

I have received the enclosed letter from my constituent and I would be grateful if you could consider her views when consulting on Ipilimumab.

Yours

PMP

All enquiries including appointments for regular surgeries
Julia Luff, Secretary Tel: 01905 763952
E-mail: peter.luff.mp@parliament.uk www.peterluff.org.uk

[redacted]

21 October 2011

House of Commons

London SW1A 0AA

Dear Mr Luff

As one of your constituents and a malignant melanoma patient I am writing to you to see if you can make representations to NICE on my behalf in order to ensure that Yervoy (Ipilimumab) is approved when they come to review it in November.

I am disappointed to hear that Yervoy has so far been declined by NICE. This is a shocking decision as clinicians and patients have been waiting for three decades for a treatment breakthrough in advanced melanoma.

I am currently undergoing chemotherapy for advanced melanoma and whilst there was only a 20% chance of the chemotherapy taking effect I have been fortunate to receive a partial response. But I understand that this is only likely to have a temporary effect and will need to be followed up with one of the more advanced drugs eg. Yervoy or a BRAF inhibitor drug (yet to be licensed).

From the research that is available, Yervoy is the first treatment to be licensed in the UK which demonstrates an overall survival benefit for people with advanced melanoma and has the backing of a number of clinicians and patient groups.

If this drug is not available on the NHS then patients will continue to have limited treatment options beyond the current standard of care that was first licensed in the 1970s.

It is also worth pointing out that over the past 25 years, the rate of malignant melanoma in the UK has risen faster than any of the top 10 cancers in the UK, this disease kills over 2000 people in the UK each year, with an average 22 years of more life lost from each melanoma death than many other cancers.

I am sending a copy of this letter to the Secretary of State and the Chair of NICE and look forward to receiving your reply.

Yours sincerely

[redacted]

[redacted]

Cc: Professor Sir Mike Rawlins, NICE and Andrew Lansley MP, Secretary of State for Health

26 OCT 2011

[redacted]

23 October 2011

Professor Sir Mike Rawlins
Chair
NICE
Mid City Place
71 High Holborn
London
WCIV 6NA

Dear Sir

I am forwarding to you a copy of my letter to my MP Meg Munn enlisting her help for the approval of Yervoy when it is reviewed in November.

Yours sincerely

[redacted]

[redacted]

23 October 2011

Meg Munn
House of Commons
London
SW1A 0AA.

Dear Meg Munn

I am writing to ask you as your constituent to make representations to NICE to ensure that Yervoy (Ipilimumab) is approved when they review it in November.

Yervoy has so far been declined by NICE despite the fact that it can save lives. Throughout the past 30 years, there has been no advancement in the treatment of malignant melanoma. NOW this drug has demonstrated dramatic effects on patients with this fearful disease but it is not available, proven though it is.

My daughter [redacted] has stage IV advanced malignant melanoma. On December the 5th, 2005, she was diagnosed with secondary malignant melanoma. Now aged 30 and married to [redacted] and mother to two year old [redacted], she has courageously endured four major surgeries, including a radical neck dissection and the excision of four tumours from her right lung. Her most recent surgery was the removal of a tumour from her hip in June this year.

Caused by UV rays from the sun, malignant melanoma is the most deadly form of cancer with there currently being no cure for this illness.

[redacted] was misdiagnosed, aged 16, following the removal of a suspicious mole. Now her chance of life saving treatment with Yervoy will be withdrawn. [redacted], our oncologist at Weston Park Hospital provides excellent care and keeps us up to date with treatment options. Unfortunately, she can only provide what the NHS offers us.

I understand that Yervoy has the backing of a number of clinicians and patient groups. It is the first treatment to be licensed in the UK, which demonstrates an overall survival benefit for people with advanced melanoma. If this drug is not available on the NHS, patients will continue to have limited treatment options beyond the current standard of care that was first licensed in the 1970s.

Over the last 25 years, the rate of malignant melanoma in the UK has risen faster than any of the top 10 cancers in the UK. Surprisingly, in [redacted] it is rising faster than in other areas. The NHS in Sheffield has released findings which show that skin cancer rates in [redacted] are "significantly higher" than the national average for England with 112 Sheffield citizens diagnosed with malignant melanoma in 2010.

Malignant melanoma kills over 2000 people in the UK each year, with an average 22 years of more life lost from each melanoma death than many other cancers.

As [redacted] mother, I appeal to you for serious consideration of the decisions made around this potentially life-preserving drug and look forward to hearing your response. I am sure you can imagine with what anguish I write to you today.

I am copying this letter to the Secretary of State and the Chair of NICE. I am looking forward to hearing from them.

Yours sincerely,

[redacted]

Cc

Professor Sir Mike Rawlins,
NICE
Mid City Place
71 High Holborn
London
WC1V 6NA

Rt Hon Andrew Lansley CBE MP
Secretary of State for Health
Department of Health
Richmond House
79 Whitehall
London
SW1A 2NL

29 October 2011

Professor Sir Mike Rawlins
Chair
NICE
71 High Holborn
London WC1V 6NA

31 OCT 2011

Re. *Yervoy* (Ipilimumab), NICE Appraisal Committee Review

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Professor Rawlins,

Below is the text of an e-mail message I have just sent my MP, Ms Charlotte Leslie of Bristol, asking her to weigh in against denying NHS beneficiaries access to *Yervoy,* the new melanoma cancer treatment, when your Appraisal Committee meets on November 16th.

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Ms Leslie, you may remember my name from your productive involvement in a successful recent quest for my British citizenship (thanks, I believe, in part to your letter to Minister Damian Green).

Today, as a grateful British subject, I e-mail you in connection with an urgent life-and-death issue with a November 4th deadline.

That is the cut-off date for input affecting the NICE Appraisal Committee's review of its decision to deny NHS use of Bristol-Myers Squibb's *Yervoy* (Ipilimumab), a break-through treatment for people with late-stage metastatic melanoma cancer - the first new treatment in 30 years.

It is in regard to this decision that I write you in the hopes you might lend your weight to tipping the scales in favour of accepting the treatment by making representations to Prof. Sir Mike Rawlins, Chair of NICE and to the Rt. Hon. Andrew Lansley, Secretary of State for Health on my behalf. When the NICE Appraisal Committee meets November 16th it will decide on whether *Yervoy* will be made available on the NHS or not.

Melanoma kills more than 2000 people in the UK every year. Over the past 25 years, the rate of malignant melanoma incidence in the UK has risen faster than any of the top 10 cancers here.

*Yervoy* is important because it is the first major break-through in an immunotherapy approach to cancer treatment. True, it is expensive and statistically it only provides an average 6-9 months of life extension but there are now cases of some people having a 46-month extension on life ... and counting!

My son, [redacted] 40 years old, happily married father of three beautiful young children and on staff at [redacted] in London has Stage 4 metastatic melanoma. You'd never know it to look at him. But he – they – have been battling his cancer for more than two years now. During that time, melanoma cancer research has been progressing by leaps and bounds. The feeling worldwide is that a truly incisive treatment/cure may not be far off. So the challenge for people like my son is to stay alive long enough to be around when that treatment *is* found.

For NICE to deny NHS access to *Yervoy* is to condemn late-stage melanoma patients to a premature death. Late-stage – and still societally productive people need all the help they can get because decisive new break-throughs are quite possible within the 46-month, indeed, even the 6-9-month life extension period.

So, it is of the utmost importance that NICE's Appraisal Committee not deny NHS access to *Yervoy* .

Could you see your way to contacting Sir Mike Rawlins at NICE and Secretary of State for Health Mr. Andrew Lansley – and, indeed, anyone else you may know on the committee - and urge them to encourage the NICE Appraisal Committee to reverse any NICE decision to deny NHS users access to this truly life-extending *Yervoy* (Ipilimumab)?

Thank you from me, my mother [redacted], and from [redacted] and his family so much for your attention to this life-and-death issue.

Sincerely,

[redacted]

[redacted]

Cc Prof. Sir Mike Rawlins, NICE
Mr. Andrew Lansley, MP, Secretary of State for Health

**David Jones MP**
**House of Commons**
**London**
**SW1A 0AA**

COPIED TO AND FAO
PROFESSOR SIR MIKE RAWLINS
NICE - CHAIRMAN

**17 October 2011**

**Dear David**

24 OCT 2011

**Skin Cancer Treatment - Yervoy (Ipilimumab)**

I trust this letter finds you fit and well.

The purpose of my writing to you, is to highlight a serious matter concerning a recent decision of the National Institute for Clinical Excellence (NICE), who are recommending that the latest available treatment for Malignant Melanoma, is not to made available on the National Health Service (NHS). The actual recommendation is unclear in this respect, and needs to be clarified. Nevertheless, to remove access to this latest treatment, which is available in America and the remainder of Europe, places the United Kingdom behind health care being provided elsewhere.

This is despite being licensed for use in this Country. Their argument is based upon their view that the treatment merely extends the life of those who have contracted the disease. Having spent a great deal of time researching what treatments are available to me, as I have personally contracted this dreadful disease, as a consequence of clinical negligence, there is a great deal of evidence to contradict this view. Indeed in several cases, treatment not only extended life, but also saw a complete response.

Clearly this decision is based on the cost of the treatment, some £75,000. I have to say, whatever the cost, should the circumstances allow the treatment to be utilised to save or extend a life, should cost play a part. Understanding that it does, as a one off payment for this treatment, surely given the success of this drug, this is inexpensive when compared to many other treatments/surgical procedures that are already available on the NHS.

This decision for clinicians and patients alike is absolutely shocking and totally unacceptable. This is the first treatment for more than three decades that can be truly considered to be a breakthrough in advanced melanoma. My research has revealed that many new treatments are being trialled presently, and should they prove to be successful, should individuals who have had their life extended by the drug Yervoy, then it may very well mean that other treatments being currently tested become available to treat or cure them.

Malignant melanoma kills over 2000 people in the United Kingdom each year, and there is clearly a growing incidence of melanoma. In the last 25 years, the rate of malignant melanoma has risen faster than any of the top 10 cancers.

Should the drug (Yervoy) not be made available on the NHS, patients will continue to have limited treatment options beyond the current standard of care that was first established in the 1970s.

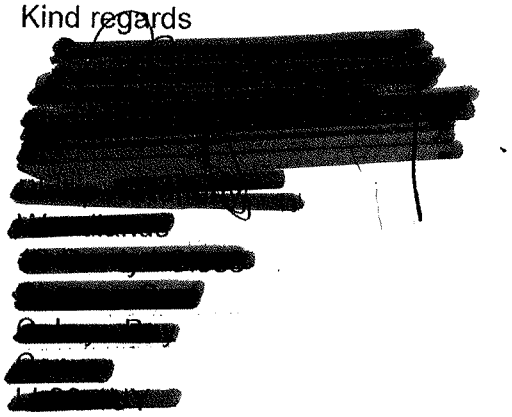
To be absolutely clear, Yervoy is the first treatment to be licensed in the United Kingdom which demonstrates an overall survival benefit for people with advanced melanoma. Yervoy has the backing of a number of clinicians and patient groups and must be made available on the NHS.

From a personal perspective, I am presently on a clinical trial, which I pray and hope has the desired effect. It is worthy of note that in trying to remain positive and determined to beat my illness, much of that hope was based on the offer of all available treatments when I was first diagnosed, Yervoy being one. Albeit I am in the midst of treatment should I need to consider an alternative treatment, I sincerely hope that the decision of NICE is reversed, as I and many others would find it somewhat unbearable to have that hope interfered with or removed.

I have written personally to you as my Member of Parliament, to respectfully request that you and fellow MP's make representations to NICE in order to ensure that Yervoy (Ipilimumab) is approved when NICE review it in November. I understand that the last date for representations is 4 November and that the matter is to be concluded on 16 November.

I do look forward to hearing from you

Kind regards



cc :

Professor Sir Mike Rawlins,
NICE Chairman
Mid City Place 71 High Holborn London WC1V 6NA

1 November 2011

Professor Sir Mike Rawlins
Chair
NICE
71 High Holborn
London WC1V 6NA

Re. *Yervoy* (Ipilimumab), NICE Appraisal Committee Review

Professor Rawlins,

Below is the text of an e-mail message my mother has sent her MP, Ms Charlotte Leslie of Bristol, asking her to weigh in against denying NHS beneficiaries access to *Yervoy,* the new melanoma cancer treatment, when your Appraisal Committee meets on November 16th.

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Dear Ms Leslie,
I am writing this to ask you to present my appeal to NICE to ensure that Yervoy (Ipilimumab), the new drug to treat advanced melanoma, be approved when NICE reviews it on November 16th (Nov. 4th is the deadline for input). It is the first treatment to be licensed in the UK that demonstrates an overall survival benefit for people with advanced metastatic melanoma.

My grandson, [redacted], who lives in London, has Stage 4 metastatic melanoma. For the past 2-3 years, he has been attending the Royal Marsden and St. George's Hospitals in London and has undergone several operations for the removal of cancerous small tumours and other treatment. He is now pinning his hopes for survival on this drug. My grandson is very young: he will be just 40 today and he is married with three very young children so he is desperately trying to go on living to bring up his children.

So far, the NHS has not finally agreed to use Yervoy, due to it's high cost, in spite of its excellent prognosis, so I am making my desperate appeal to you to ask the Rt. Hon. Andrew Lansley, Secretary for Health, to make Yervoy available to the NHS for patients who might otherwise die very soon. Perhaps you could also contact Sir Michael Rawlins who is Chair of NICE and whose address is 71 High Holborn, London WC1V 6NA. The NICE Appraisal Committee Review will be meeting very soon, on Nov. 16th, to make their decision on whether to provide Yervoy to NHS patients but the deadline for input is 4pm on November 4th, so my appeal is rather urgent.

I know you must have your time in great demand, but this is a desperate appeal which could save the life of a young father, a loving husband, son and grandson and I would appreciate your help with all my heart.

Yours sincerely,

[redacted]