CHARLOTTE LESLIE MP

HOUSE OF COMMONS
LONDON SW1A 0AA

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

2nd November 2011
Our ref: FR/CC

Dear Sir Michael

Ref: [redacted]

My constituent, [redacted], has asked that I contact you on her behalf to appeal for approval for Yervoy (Ipilimumab), a new drug to treat advanced menanoma. I enclose a copy of her email.

I understand that [redacted] is very concerned about her grandson for whom this drug appears to be his last hope.

I would be very grateful if you consider my constituent's appeal.

Yours sincerely

Charlotte Leslie

Charlotte Leslie MP

Member of Parliament for Bristol North West
T: 020 7219 7026 F: 020 7219 0921 E: charlotte.leslie.mp@parliament.uk
www.charlotteleslie.com

[redacted]

Subject: FW: URGENT: FW[redacted]
Attachments: [redacted] NICE.docx

From: [redacted]
Sent: 30 October 2011 10:31
To: LESLIE, Charlotte
Subject: [redacted]

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 menanoma, be approved when NICE reviews it on November 16th (Nov. 4th is the deadline for input). It is the first treament 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]

[redacted]

[redacted]

31st October 2011

Mr Jim Dowd MP
House of Commons
London
SW1A 0AA

Dear Mr Dowd

Re: Melanoma, Yervoy (Ipilimumab)

My name is [redacted] and I live within your constituency. My brother [redacted], aged 50, has Melanoma, which has now spread to his lungs.

I am writing to see if you can make representations to NICE on my behalf in order to ensure that Yervoy (Ipilimumab) is approved when NICE review it in November 2011.

I understand that Yervoy has so far been declined by NICE and this fills me with great sadness as this is the drug that my brother currently needs in his fight against the disease. This is a shocking decision as clinicians and patients have been waiting for three decades for a treatment breakthrough in advanced melanoma.

[redacted] battle with Melanoma began earlier this year and he has so far undergone two operations to remove malignant sites. He now has a third site on his lungs, which cannot be operated on. It is only through his personal determination to fight the disease via any means that two of his malignant sites have been detected. Twice he has signed up to drug trials and twice he has been knocked back because malignant areas have been found via CT scans. Had he not been signed up to the trials the malignancies would not have been detected so early and his chances of survival would have shortened considerably. [redacted] will hopefully be successful in being accepted onto the Yervoy drug trial, but if he is not then he, like many more, will miss the opportunity to prolong his life. [redacted] has a wife and two children, who are now blossoming into fine young adults. Their lives will be devastated if he is not around to support them during their continued growth and to see them marry and raise families of their own. That's all cancer suffers ask for, a little more precious time. [redacted] is an active member of his community, serving on his parish council and he is the manager of a local football club. His premature death would be a great loss to his community.

As a family we have been both supportive and positive for [redacted], full of hope that he will overcome his cancer as my father did in the last year, but being told that now there is little that can be done for [redacted] it has become more apparent that the necessary treatment to help him and others suffering Melanoma should be available on the NHS.

No one cancer should be singled out as a priority, all treatments should be available to all. The people who play lotto with our lives can afford the treatment privately, families like mine simply can't, even if we pooled all our resources together. It's up to people like me to make a stand and ask what price do you put on a life. Please make a stand with me and shout for the lives of many in this Country.

I understand that Yervoy has the backing of a number of clinicians and patient groups. Yervoy 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.

Skin cancer is the second most common cancer in the United Kingdom, with about 40,500 new cases each year, of which 6,000 are malignant melanomas. About 1,500 people die from melanomas in Britain every year. The rate of malignant melanoma in the UK has risen faster than any of the top 10 cancers in the UK.

In 1990/91 [redacted] fought in the Gulf War. He was prepared to give his life for his Country. All he is asking now is that his Country gives something back for his life.

I look forward to your support.

Yours sincerely

[redacted]

[redacted]

cc. Professor Sir Mike Rawlins, 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

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 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]

14 October 2011

Miss Esther McVey MP
House of Commons
London
SW1A 0AA

18 OCT 2011

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)

[redacted]

[redacted]

[redacted]

- 1 NOV 2011

[redacted]

[redacted]

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]

[redacted]

1/1/11

Professor Sir Mike Rawlins
Chairman of NICE

Dear Professor Sir Mike Rawlins

I wish to voice my disbelief 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.

My friend has metastatic melanoma. A true gentlemen and family man. Finding out that he had cancer was heartbreaking for his friends and family.It is even more heartbreaking to know that there is a drug which may help but it is impossible for him to access. This is a horrible aggressive disease. This drug is valuable even from a palliative point of view.

Use of this drug will allow it to be developed to ultimately find a cure. Melanoma treatment has been at a standstill for 30 years. This is a coldhearted decision which would stunt the development of this drug for how long? another 30 years?

I wholeheartedly believe this treatment should be available throughout the UK with immediate effect. Please ensure that there is access to this drug as soon as possible.

I look forward to hearing from you.
Thank you for your help in making this treatment available for melanoma patients.

Yours sincerely

[redacted]

[redacted]

2nd November 2011

Julian Sturdy, MP
House of Commons
London
SW1A 0AA

- 7 NOV 2011

Dear Sir,

I am a member of your constituency and in June of this year I was diagnosed with Stage IV Malignant Melanoma.

I am writing to you to see if you can make representation to NICE on my behalf in order to ensure that Yervoy (Ipilimumab) is approved when NICE review it in November. I was very disappointed to hear that Yervoy has so far been declined by NICE. This is a shocking decision as clinicians and patients have been waiting three decades for a treatment breakthrough in advanced melanoma.

I'm a 45 year old female with a husband and two young children, aged 13 and 9 years. I was originally diagnosed with a stage 1b malignant melanoma in January 2005 and at the time thought that I had found the disease early and had a lucky escape. Unfortunately in March this year the melanoma returned in my abdomen and left lung and so far this year I have had part of my lower abdominal muscle removed and part of my left lung. I have worked in the NHS for over 25 years now caring for patients with heart conditions and am very aware of the vast improvements that have been made in the care of this patient group due to the support and leadership from senior clinicians. I very recently started a new job as a commissioning manager for the NHS and so am very aware of the current financial crisis that is affecting decision making within the NHS; however there is a growing incidence of malignant melanoma in the UK and it is rising quicker than any of the top 10 cancers in this country. It kills over 2000 people in the UK each year.

Yervoy is the first treatment to be licensed in the UK which demonstrates an overall survival benefit for people with advanced melanoma and it has the backing of a number of clinicians and patient groups. 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. Although I do not require this medication currently I may need it in the future, I would like to be around to watch my children grow up.

The Karen Clifford Skin Cancer Charity and Factor 50 charity have been campaigning for improved treatment for advanced melanoma following the NICE refusal and today the House of Commons has asked NICE to reconsider its draft guidance in the Early Day Motion 2362.

I am sending a copy of this letter to the Secretary of State and the Chair of NICE and I look forward to hearing from you.

Yours faithfully,

[redacted]

[redacted]

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

28/10/2011

Professor Rawlins

I am writing to express my extreme 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.

Melanoma is increasing in incidence and 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. It kills over 2000 people in the UK each year. It is the most aggressive form of cancer, depriving sufferers an average of 22 years of life in comparison to other forms of the disease.

Yervoy has the backing of a number of clinicians and patient groups. Unfortunately it has so far been declined by NICE. This is a shocking decision as clinicians and patients have been waiting three decades for a treatment breakthrough in advanced melanoma.

There have been no effective treatments for melanoma until now. Ipilimumab has met the criteria for being a life-extending, end-of-life treatment. The trial evidence presented for this consideration is robust: 30% of people treated with Ipilimumab will experience an improvement in median survival, and 10% of people will have long-term benefits. Therefore it should be the gold standard in advanced melanoma treatment. Ipilimumab is a landmark drug which will greatly affect the quality of lives of a number of people.

Cost is a major factor for Ipilimumab not having already been approved. However, costs have not been directly compared to those incurred by current melanoma treatment. In addition I believe that the contribution made by young people with melanoma who work, raise families and contribute greatly to the economy has been inadequately factored in.

It has taken more than 30 years for a significant breakthrough in melanoma treatment to occur and I believe this timespan partly explains the costs and makes them justifiable. New drugs are always expensive. However, competition, widespread and longterm use will naturally lower prices. Furthermore, a national procurement contract would remove cost variations and ensure a better and more reasonable price.

Approximately 400–500 people with advanced melanoma progress on to second-line treatment each year in the UK. Although costs per patient are high it is restricted to a very small group of people.

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.

I would be very grateful for your help with his matter not only for my father and my family, but for all of those suffering from advanced melanoma.

Yours sincerely

[redacted]

[redacted]

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

18 OCT 2011

16th October 2011

Dear Professor Rawlins,

Please find enclosed the copy of a letter I have sent to my MP Rt Hon Hilary Benn regarding the drug Yervoy having been declined by NICE.

Yours sincerely,

[redacted]

[redacted]

[redacted]

Rt Hon Hilary Benn MP
House of Commons,
London,
SW1A 0AA

16th October 2011

Dear Mr Benn,

I am one of your constituents and I am a melanoma patient. I am writing to you in the hope that you can make representations to NICE on my behalf in order to ensure that Yervoy (Ipilimumab) is approved when NICE review it in November. I am very 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 first diagnosed with malignant melanoma at the age of 38 and it appeared that surgery had cleared me of the disease. However 2years ago, at the age of 51, it was found to have returned and spread to my lymphatic system. I had just retired after serving 30 years in the West Yorkshire Police and I was looking forward to a new chapter in my life spending time with my grandchildren and studying for a degree. Major surgical intervention has left me clear of melanoma at present but my odds are 50/50 for the disease to return in an advanced state. I am now the sole carer of my elderly mother-in-law who now suffers from dementia and my fear is that, should the disease become advanced and any possible treatment not be available to me, I will leave my husband struggling to care for his mother and I will never get the chance to see my newest grandchild who lives in Australia. The disease has also affected other members of my family in that my only sibling, at the age of 43, had a dysplastic (pre-cancerous) mole removed

and his daughter also suffered the same procedure at the age of 18. Research shows that melanoma may possibly be hereditary therefore my close relatives are also at risk of contracting advanced melanoma in the future. This means the decision by NICE is very important to my family.

I understand that Yervoy has the backing of a number of clinicians and patient groups and that 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. Also, the numbers of those diagnosed with the disease are growing and 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. This disease kills over 2000 people in this country each year, with an average of 22 years of more life lost from each melanoma death than many other cancers and leaving many young families without a parent.

I am copying this letter to the Secretary of State for Health and the Chair of NICE. Thank you for your assistance and I look forward to hearing from you.

Yours sincerely,

[redacted]

[redacted]

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

[redacted]

18 OCT 2011

16.10.2011

Dear Sir Paul Beresford,

I am one of your constituents, and am a 52 year old advanced melanoma cancer patient, with stage 4 melanoma (The most final stage).

At present I am taking part in a trial of a drug called vemurafenib under [redacted] at the Royal Marsden hospital in London. This drug has been working well at reducing the size of my tumours, however the previous trials have shown that the drug does not have a long term effect, and patients become immune to it.

Therefore I am writing to you asking you to make representations on my behalf to NICE to try and get Yervoy (Ipiliumab) approved when NICE review it at the start of November 2011.
Yervoy has been shown to have a long term effect at reducing tumours in melanoma patients. In fact, my doctor [redacted] at the Royal Surrey hospital has patients who are still alive and have a good quality of life 4 years after taking Yervoy.
As my present drug is unlikely to have a long term effect, my only hope for life is with Yervoy.
You can imagine the stress any cancer patient is under, especially one who is in the terminal stages of the disease. Therefore you can imagine how increased that stress becomes when you hear that a drug which could extend your life is denied on financial grounds. Although I have a short life expectancy (Without any drugs I have been given one year, but hopefully vemurafenib will extend that), I am currently well, leading an active life and still working as a Trading Standards Officer for Surrey County Council.

I found out that I had stage 4 Melanoma in March this year, and was devastated as I was previously stage one, and somehow jumped to the final stage. My doctors told me that I was very lucky as advances had recently been made in treatment, the first for 30 years and with these two new drugs, Vemurafenib and Yervoy, my life could well be extended for 5 years or more. However if NICE refuse Yervoy, my life will be cut even shorter, which is shocking when I know that treatment is available.
I was always grateful that in this country one did not have to worry about health, as the NHS was always there. TV shows from America had people turning to crime to raise money for a loved one who needed Cancer treatment, and I thought how lucky I was to live in a country where that could never happen. Now it seems I was wrong, and if NICE refuse Yervoy, when the time comes I will have to remortgage my house to raise money for treatment.

Yervoy is the first treatment to be licensed in the UK which shows an overall survival benefit for patients like myself with advanced melanoma. Melanoma is becoming more and more common and kills 2000 people in the UK every year. If

NICE do not approve Yervoy, the drug companies will not continue research in this area, and the number of people dying will increase.
It is something I never thought I would have to do, write to people begging for an extension to my life. It is something I would definitely prefer not to have to do, but unless I speak up, I feel that NICE will carry on without realising the consequences of their action.
I have two daughters who have just begun University. I would dearly love to see them graduate, marry and have families, but without Yervoy I cannot see this happening. I know other patients with advance Melanoma have children younger than mine, and we would all like to be alive to support our children for as long as possible, and Yervoy would extend our time with them, and our husbands, wives etc. Therefore I do hope that you can add your support for Yervoy when NICE review whether to allow the NHS to use it in November.

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

Yours sincerely,

[redacted]

Cc: Professor Sir Mike Rawlins,
Chair,
NICE,
Mid City Place,
71 High Holburn,
London WC1V 6NA

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

25 OCT 2011

HOUSE OF COMMONS
LONDON SW1A 0AA

All replies:
Oldham Office
11 Church Lane
Oldham OL1 3AN
Tel-0161 626 5779

National Institute for –
Health & Clinical Excellence
Midcity Place
71 High Holborn
London
WC1V 6NA

Our Ref: SB/WORT01001/01110710
Your Ref:

21 October 2011

Dear Sir/Madam

Re: Availability of Yervoy – Ipilimumab

I am writing to you on behalf of a constituent who is suffering from advanced melanoma. I understand the above drug is being hailed as the biggest breakthrough in the treatment of advanced melanoma in 40 years, but there is a reluctance to fund the drug.

Statistics indicate that melonoma rates have risen significantly over the past 25 years, killing over 2000 people every year, with an average of 22 more life years lost per person than any other cancer. I understand the drug known as Yervoy is expensive, but making the drug available could potentially make a huge difference to the life expectancy of sufferers.

I understand a review of your decision not to fund the drug is due to take place in early November, I would like to add my support to a reversal of this decision in light of the backing of clinicians and other patient groups and would be most grateful if you would consider my representation on behalf of my constituent.

Yours sincerely

Michael Meacher

The Rt Hon Michael Meacher MP
Oldham West & Royton
Including Chadderton & Hollinwood

Maria Miller MP
Member of Parliament for Basingstoke

House of Commons
London SW1A 0AA
Tel: 020 - 7219 5749
Fax: 020 - 7219 5722

Mr Andrew Dillon CBE
Chief Executive
NICE
MidCity Place
71 High Holborn
London WC1V 6NA

25 OCT 2011

Our ref: MM11930

19 October 2011

Dear Mr Dillon

[redacted]

I enclose a copy of an emailed letter I have received from my constituent [redacted] of the above address.

As you will see from his letter, [redacted] is concerned about the NICE decision on the drug Yervoy (Ipilimumab) used for the treatment of melanoma. As someone who has recently had two malignant melanomas, my constituent feels that this drug should be made available on the NHS for treatment of malignant melanoma.

I would be grateful if you could look into the points raised by my constituent and let me know your response.

Yours sincerely,

Maria Miller

Enc

Email: maria.miller.mp@parliament.uk

[redacted]

From: [redacted]
Sent: 14 October 2011 13:28
To: MILLER, Maria
Subject: Yervoy declined by NICE for Advanced Melanoma patients

[redacted]

14th October 2011

Dear Mrs Miller,

I am 37 years and this year was diagnosed with Malignant Melanoma, not only once, but twice. A "bad" mole was discovered on my arm in January 2011 which results in surgery to remove the mole and some surrounding tissue. Thankfully the results came back that no spread had been detected. In June 2011 a second "bad" mole was found on my chest, which again resulted in surgery to remove. Thankfully again this came back show no spread. I will now be monitored by a Dermatologist for the next 5 years to look for any further signs or spread.

During the past 9 months I have obviously become increasingly interested in the medical developments for Melanoma and today I am deeply shocked to discover that a new treatment Yervoy (Ipilimumab) has been declined by NICE for use in the NHS. This is a shocking decision as clinicians and patients have been waiting for three decades for a treatment breakthrough in advanced melanoma.

Yervoy is the first treatment to be licensed in the UK which demonstrates an overall survival benefit for people with advanced melanoma. 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. 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. The treatment was approved by drugs regulators in the United States in March and was in May recommended for approval in Europe by the European Medicines Agency. It seems shocking that in the UK that NICE can make a decision that affects peoples lives and treatments available to them.

My own personal situation is that I do not need the drug today as I only have Stage 1 Melanoma. Depending what happens with myself and if I find my Melanoma has spread then this medicine could be something that I would really need to extend my life further.

I am writing to you as my MP to ask you to make representations to NICE on my behalf in order to ensure that Yervoy (Ipilimumab) is approved when NICE review it again in November.

Best regards,

[redacted]

WILLIAM CASH, M.P.

HOUSE OF COMMONS
LONDON SW1A 0AA

Andrew Dillon, Esq.,
National Institute for Health and Clinical Excellence
MidCity Place
71 High Holborn
London
WC1V 6NA

31 OCT 2011

Wednesday 26th October 2011

Dear Mr. Dillon,

I have received the attached letter from my constituent who raises issues which come under your responsibility.

I would be grateful if you could address all of the issues raised and come back to me, **naming** my constituent in your response.

Yours ever,

Bill

[redacted]

[redacted]

19/10/11

Dear Mr Lord,

As one of your constituents and a grandmother of a 15 year old boy with malignant melanoma, I would ask you to make representation on my behalf to ensure that the drug "Yervoy" is approved for use in the N.H.S. when it is reviewed by NICE in November. The drug is the first glimmer of hope for sufferers of advanced melanoma, for which until now, there has been no treatment. Yervoy has the backing of many clinicians and

patient groups.

Melanoma often attacks young people – as my grandson – and frequently they are parents of young children and every extra day of life is precious to them.

Yours sincerely

[redacted]