

DAVID JONES MP/AS



HOUSE OF COMMONS

LONDON SW1A 0AA

Appraisal Committee  
National Institute for Health and Clinical Excellence  
MidCity Place  
71 High Holborn  
LONDON  
WC1V 2NA

1<sup>st</sup> Nov 2011  
Our Ref:LDN5210.CO

Dear Sirs

**MY CONSTITUENT :** [REDACTED]

As you will be aware I have been consulted by my above named constituent, who has corresponded directly with Professor Sir Michael Rawlins. Professor Rawlins has written to [REDACTED] confirming that his letter to me (copied to Professor Rawlins) dated 17<sup>th</sup> October, 2011, will be taken into account by the committee in considering whether Yervoy should be available for the treatment of melanoma.

I would be grateful if the committee would also please take this letter into account when considering the matter.

The committee will of course be aware that malignant melanoma kills over 2,000 people in the United Kingdom each year. In the last 25 years, the rate of malignant melanoma has risen faster than any of the top cancers.

Yervoy is the first new treatment to show survival benefits in patients with metastatic malignant melanoma. [REDACTED], senior lecturer at the University of Manchester and Honorary Consultant in Medical Oncology at the Christie NHS Foundation Trust, has observed that:

"The authorisation of Ipilimumab represents a real advance in the treatment of patients with advanced melanoma as this is the first treatment for 30 years in the UK to extend patients' life expectancy."

DAVID JONES MP/AS (Clwyd West/Gorllewin Clwyd)  
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The outcomes of the use of Yervoy in clinical trials were sufficiently positive for the drug to become swiftly licensed for use in the United States and Europe. The rapidity with which Yervoy has been licensed demonstrates the views of senior health professionals throughout the world that this drug is worthy of being available as a treatment. I note that the submissions of [redacted] and [redacted] to the Institute attest to the efficacy of Yervoy in the treatment of melanoma. Certainly, as time passes, the number of individuals treated with Yervoy who experience long term benefit, a stabilisation of the disease, or no evidence of disease, is a significant improvement on the statistics referable to previously available treatments.

The issue of side effects has led to clear guidance being available to oncologists and available clinical networks should be able to provide sufficient support to consider and agree approaches. Side effects experienced by existing treatments can also be significant and adverse, and on many occasions with no real benefit. My constituent poses the very potent question:

"Why do we continue to use a treatment that has little or nor real benefit in many cases?"

The continued use of Yervoy is, I would submit, essential, not simply to provide hope and best treatment to the increasing numbers of people diagnosed with melanoma, but also to ensure that practitioners obtain a better understanding of what Yervoy is able to achieve as a treatment.


I would also strongly submit that to withdraw the availability of this treatment in the United Kingdom will place Britain behind the rest of the world in terms of the treatment of melanoma.

The issue of cost is of course a consideration that the Appraisal Committee will have to address. In this context, I would urge that discussions take place with Bristol-Myers Squibb with a view to negotiating the issue of cost.

Many thousand melanoma sufferers throughout the United Kingdom are looking to the committee for hope of securing a treatment for this dreadful disease. I would strongly urge, therefore, that this letter be taken seriously into account by the committee.

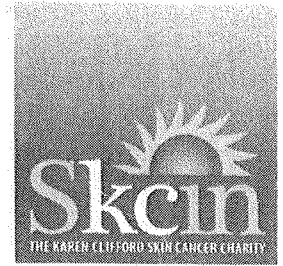
I should be most grateful if you would please acknowledge safe receipt of this letter.

Yours faithfully

  
David Jones, MP/AS (Clwyd West/Gorllewin Clwyd)  
E-mail: [jonesdi@parliament.uk](mailto:jonesdi@parliament.uk) – [www.davidjonesmp.com](http://www.davidjonesmp.com)



MYFANWY TOWNSEND  
MELANOMA RESEARCH FUND



Sir Andrew Dillon  
Chief Executive, NICE  
Mid City Place  
71 High Holborn  
London  
WC1V 6NA

1 NOV 2011

28 October 2011

**Ipilimumab for previously treated advanced (unresectable or metastatic) malignant melanoma**

Dear Sir Andrew,

We are writing to urge you to rethink your preliminary decision not to recommend Ipilimumab (Yervoy). This is an extremely disappointing decision and one that will be a devastating blow to people with advanced melanoma.

Clinicians and patients across the UK have been waiting for three decades for a treatment breakthrough in advanced melanoma and we believe that this treatment fulfils a real unmet need for this patient group. We are extremely concerned that if the draft NICE guidance on Ipilimumab, published 14 October, is not overturned it will mean that patients will continue to have limited treatment options.

More than 11,700 people are diagnosed with malignant melanoma each year and it kills over 2,000 people. This decision by NICE is even more devastating because, as you will be aware, the incidence of melanoma is on the rise in the UK. Over the last 25 years, the rate of malignant melanoma has risen faster than any of the top 10 cancers and it is the second most common cancer among young adults aged 15-34 years. A recent study featured in the British Journal of Cancer predicts that the incidence rate of melanoma will increase more than any other cancer by 2030, rising by 52 per cent for both men and women.

We urge NICE to reconsider its draft guidance at the Appraisal Committee meeting on 16 November and issue a positive response to patients across the NHS, many of whom are devastated by this decision especially in light of the Cancer Drugs Fund coming to an end in 2014. We ask you to re-examine the clinical evidence and also give extra consideration for the fact that this aggressive disease disproportionately affects young people – many of whom have young families. As NICE has acknowledged “Ipilimumab represents a step change in the treatment of advanced melanoma.” It is vital that NICE consider the innovation behind this treatment and the subsequent substantive benefit to patients. If not approved, the hopes of many of our patients and supporters will be dashed.

Yours sincerely,

**Richard Clifford,**  
Founder and Trustee, SKCIN  
Chairman, Skin Cancer UK

**Gill Nuttall**  
Founder, Factor50

**Harry Townsend**  
Founder and Chair  
Myfanwy Townsend Melanoma  
Research Fund

cc Lord Howe (Parliamentary Under-Secretary of State for Health)  
cc Professor Sir Mike Richards CBE (National Clinical Director for Cancer)  
cc Professor Sir Mike Rawlins (Chair, NICE)  
cc Dr Jane Adam MB BS, MRCP, FRCR (Chair, Appraisal Committee A)



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

Please note given the limited time for response I have also sent this letter to your constituency office and email addresses

[REDACTED]

Please follow this link for further information on the decision of NICE -  
[http://www.factor50.org.uk/pdf/patient\\_pack.pdf](http://www.factor50.org.uk/pdf/patient_pack.pdf)





Rt Hon Patrick McLoughlin MP  
House of Commons  
London SW1A 0AA

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

19<sup>th</sup> October 2011  
Ref: PM/AB/Tarr

24 OCT 2011

Dear Sir Andrew

Please find enclosed a letter I have received from my constituent, [REDACTED]

As you will see, [REDACTED] is very keen to see that the drug Yervoy is approved when NICE review the product in November.

I would be grateful if you could ensure that [REDACTED] points are taken into account during the consultation process and I would be grateful for a reply I may pass to [REDACTED] in due course.

Yours sincerely

*Patrick McLoughlin - Working for Derbyshire Dales*  
020 7219 3511  
E-mail: [patrick.mcloughlin.mp@parliament.uk](mailto:patrick.mcloughlin.mp@parliament.uk)

[REDACTED]

Rt. Hon. Patrick McLoughlin

House of Commons

London W2W 1A 0AA

14<sup>TH</sup> October 2011

Dear Mr McLoughlin

I am writing to you, to ask you to make representation to NICE , in order to ensure that Yervoy (ipillmumab) is approved when Nice review it in November.

My Daughter in Law has been diagnosed with advanced melanoma. She is just 35 years old with a young family, a 6 year old daughter, a 4 year old son and a 3 month old baby son. Surely it must be her human right not to be denied a treatment that could give her a chance to live longer and the right to have a family life for as long as possible for herself, her husband and her children.

We are bitterly 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 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 cure that was first licensed in the 1970s.

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.

Patient's hopes have been dashed. It is devastating that many patients have been left with little hope.



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]

[REDACTED]



[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]

03/11/2011

Mr John Glen MP  
House of Commons  
London  
SW1A 0AA

Dear John,

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

**Request to make representation to NICE to approve the use of Yervoy**

As a constituent of [REDACTED] I am writing to ask that you do all you can to ensure that Yervoy (Ipilimum) is approved when NICE review it later this month November 2011. My personal interest in this cause is that a very close friend, mentor and hero urgently needs this treatment. This person has enriched many lives through his tireless effort within our community, as football manager and coach to all ages and abilities. He has also served our country in the Armed Forces. All his life he has given so much to others and time is running out for us to do anything in return. In writing this letter, I feel I am doing [REDACTED] a disservice, and wish I knew how to do more. Ironically, [REDACTED] was campaigning for this treatment prior to learning of his own illness.

I was 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 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 Yervoy 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 1970's. During this time there has been a growing incidence of melanoma. Over the past 25 years the rate of malignant melanoma has risen faster than any of the top 10 cancers in the UK. It 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 copying this letter to the Secretary of State and the Chair of NICE.

I look forward to hearing from you.

Yours sincerely,

[REDACTED]  
[REDACTED]



- 2 NOV 2011

RT HON PAUL GOGGINS MP  
HOUSE OF COMMONS  
LONDON  
SW1A 0AA.

[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]  
01/11/2011

Dear Sir,

I am one of your many constituents and am currently caring for my 30 year old daughter [REDACTED] who was diagnosed with advanced melanoma grade 3c in February this year.

She underwent extensive surgery and is currently receiving adjuvant chemotherapy (Abiraterol) every three weeks until June 2012 at The Christie hospital Manchester due to her significantly high risk of recurrence.

Both my mother and father-in-law, [REDACTED] paternal grandparents were also diagnosed with malignant melanoma at a young age and sadly passed away when their tumours reached stage 4.

They both trialled the drug Interferon at The Christie before their deaths in 1985.

I am writing to you to see if you can make representations to NICE on our behalf in order to ensure that the new drug YERVOY (Ipilimumab) is approved when NICE review in November.

We are highly 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 breakthrough treatment in Advanced melanoma.

YERVOY has been used by thousands of clinicians including [REDACTED] my daughter's oncologist.

YERVOY is the first treatment to be licensed in the UK which demonstrates an overall survival benefit for people with advanced melanoma.

If the 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 1970's.

Malignant melanoma kills over 2,000 people in the UK each year, with an average 22 years of more life lost from each melanoma death than many other cancers.

There is a growing incidence of melanoma; 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.

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

I look forward to hearing from you.

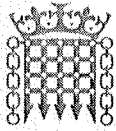
Yours sincerely

[REDACTED]

(a very concerned mother.)

cc: Professor Sir Mike Rawlins NICE

Andrew Lansley MP Secretary of State of Health



# DAN ROGERSON MP

Liberal Democrat MP for North Cornwall  
*ES Livrel Weriniethor a-barth Kernow Gledh*  
[www.danrogerson.org](http://www.danrogerson.org)

Professor Sir Mike Rawlins  
Chair, NICE  
Mid City Place  
High Holborn  
LONDON  
WC1V 6NA

Ref: DR/PE/111031Skcin  
PLEASE QUOTE IN ALL CORRESPONDENCE

31<sup>st</sup> October 2011

Dear Sir Mike,

## NICE Technology Appraisal of Yervoy (Ipilimumab)

I understand that NICE Appraisal Committee A is currently undertaking a Technology Appraisal for Yervoy (Ipilimumab). Yervoy has been licensed for the treatment of adult patients with metastatic melanoma who have received prior therapy.

I am disappointed to learn of NICE's recent Appraisal Consultation Document (ACD), which states that access to Yervoy (Ipilimumab) has been denied. I would like to seek reassurances that you are taking heed of the messages from patients, clinicians and patient groups and ensure their voices are heard as part of the consultation process.

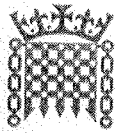
This decision by NICE is particularly disappointing as this treatment option for people with advanced melanoma is innovative and addresses an unmet need. It is particularly important to emphasise this given that the incidence of melanoma is on the rise – over the last 25 years, in the UK the rate of malignant melanoma has risen faster than any of the top 10 cancers. In addition this aggressive disease disproportionately affects younger people and there is an average 22 years of life lost from each melanoma death - more than many other cancers. There is a higher than average incidence rate in my constituency of North Cornwall, as well as across the rest of the Duchy of Cornwall.

Yervoy (Ipilimumab) is the first licensed treatment in the UK since the introduction of the current standard of treatment in the 1970s. I urge NICE to look again at its decision and recognise the extent of the huge unmet need in this disease area. There is a danger that if Yervoy is not approved, patients will continue to have limited treatment options beyond the current standard of care.

House of Commons, London SW1A 0AA  
*Chi an Gemmynyon, Loundres SW1A 0AA*  
Telephone 020 7219 4707 Fax 020 7219 1018

4 Tower Street, Launceston, Cornwall PL15 8BQ  
*4 Stret Tour, Lannstefan, Kernow PL15 8BQ*  
Pellgowser 01566 777123 Pennskrifenn 01566 772122

All personal information will be treated as confidential, but the MP may allow access to it by authorised staff, if this is necessary to help and advise you and may pass it on to official agencies where it will help your case. The MP may contact you from time to time to keep you informed. Please let him know if you have any problems with these arrangements.



Yours sincerely,

**DAN ROGERSON MP**

A handwritten signature in black ink, written over the printed name. The signature is stylized and cursive, starting with a large 'D' and ending with a long, sweeping tail.



[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]  
[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. 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. My father suffers from this condition and as such this decision is devastating and incomprehensible to my family.

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]

PAULINE LATHAM OBE MP

Mid Derbyshire



HOUSE OF COMMONS

LONDON SW1A 0AA

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

24 OCT 2011

Our ref: MM3667/DG

19th October 2011

Dear Professor Sir Mike Rawlins,

I am contacting you on behalf of my constituent, [REDACTED]

She has contacted me on behalf of her sister, who has been diagnosed with malignant melanoma, regarding the NICE review of Yervoy (Ipilimumab) treatment due in early November.

Please find her letter attached. I would be grateful if you could please respond to the points she raises.

I look forward to hearing from you.

Yours sincerely,

Pauline Latham OBE MP

Westminster Office - Tel: 020 7219 7110 Fax: 020 7219 2834

Constituency Office - The Old Station, Station Road, Spondon, Derby DE21 7NE Tel: 01332 676679

Email: pauline.latham.mp@parliament.uk Website: www.paulinelatham.co.uk

Mr X A McKenzie  
[Redacted]  
[Redacted]  
[Redacted]  
[Redacted]



Pauline Latham MP  
House of Commons  
London  
SW1A 0AA  
15 October 2011

Dear Ms Latham

I am within your constituency and my sister in law has been diagnosed with malignant melanoma.

Could you please make representations to NICE on my behalf in order to ensure that Yervoy (Ipilimumab) is approved when NICE review it in early November.

My family have been saddened 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 sister in law was diagnosed with malignant melanoma in early September 2011 after being ill for several months and being misdiagnosed with a benign tumour during the late stages of pregnancy. After her son was born she did not improve and her health continued to deteriorate, she was then told that she had late stage melanoma which by this point had spread to her brain, spleen, lungs and liver.

Our family is devastated by this and as you would expect are praying for a miracle, however to have any chance of improvement she needs to have the best medical treatment available including the latest breakthrough treatments in this disease. At this stage we do not know whether Yervoy would help but it is imperative it be available as an option for my sister in law and the thousands of other melanoma patients. She has three young children, the youngest being only 14 weeks old. She should be celebrating the birth of her son but at this point in time she cannot even hold him.

When I look at her I cannot recognise her such is the effect this has had on her in the six weeks since she was diagnosed. She is only 35 years old and should be entitled to anything that could help her keep her precious life and her family keep her with them for longer to enable her to see her children grow and to give them a chance of remembering her.

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

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 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.

I am sending a copy this letter to the Secretary of State and the Chair of NICE.

I you look forward to hearing from you as soon as possible.

Yours sincerely, [Redacted]

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

[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]

Professor Sir Mike Rawlins  
Chair NICE

Dear Professor Sir Mike 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 NICE has jurisdiction over drug availability in England and Wales, but 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. 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 to others who care for those with this cancer.

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

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.

Please remember this drug will make a real difference to these patients and families lives.

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]

[REDACTED]



[REDACTED]

[REDACTED]

[REDACTED]

[REDACTED]

Rehman Chishti MP

House of Commons

London SW1A 0AA

- 1 NOV 2011

29<sup>th</sup> October 2011

Dear Mr Chishti,

As a member of your constituency, 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 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 for three decades for a treatment breakthrough in advanced melanoma.

I am writing on behalf of a very old friend whose daughter in law is suffering from advanced melanoma. [REDACTED] is a young mum who has three children under five. She recently lost her own mother because of a malignant brain tumour. Yervoy may be able to give her a few extra months with her young family if not a complete cure, so that they will have more memories of their mum

I understand that 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, access to it will be very limited and only to those who can afford it. [REDACTED], I know, cannot afford to finance the drug treatment herself.

The rate of malignant melanoma in the UK has risen faster than any of the other top ten cancers and it kills over 2000 people in the UK each year. When there is a treatment available it would be criminal not to give all who need it access to it – it is not just those with the disease that are in need but their families as well.

I am sending copies to this letter to the Secretary of State for Health, Andrew Lansley MP and the Chair of NICE, Professor Sir Mike Rawlins.

Yours sincerely

[REDACTED SIGNATURE]

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





[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]

John Glen MP  
House of Commons  
London  
SW1A 0AA

Dear Mr. Glen,

I am one of your constituents living in the [REDACTED] area and I have recently been informed that a good friend and mentor to me, [REDACTED] has been diagnosed with advanced stages of Malignant Melanoma.

[REDACTED] has been advised that the drug Yervoy (Ipilimumab) is his best chance of prolonging his life, therefore I am writing to yourself to ask if you can make representations to NICE (National institute for Health and Clinical Excellence) to ensure that Yervoy (Ipilimumab) is approved when the use of this drug is reviewed in November this year.

I struggle to believe that NICE have so far declined the use of Yervoy within England and Wales, especially when it has been clinically proven that Yervoy has a 46% success rate in extending the lives of patients with Melanoma from 6 – 9 months to a year or more.

As stated earlier I am writing to you on behalf of [REDACTED] has been involved in local football in the [REDACTED] area for many years and has been extremely successful, along with his success [REDACTED] has been a great mentor to all players he has coached in his years with in football.

Along with being a great ambassador for local Football in [REDACTED], [REDACTED] is someone who I am proud to have as a friend.

[REDACTED] is well respected around the [REDACTED] area and his illness has come as a massive shock to all of those who know him, and I personally would like to do everything I possible could to help, not only with his fight against Melanoma, but to help ensure that this drug is available to all of those people who really need this drug.

Yervoy is a drug which has the backing of many clinicians and patient groups and is the first treatment to be licensed in UK which demonstrates an overall survival benefit for people with advanced Melanoma.

I urge you to help in our fight to get this drug available to patients in England and Wales. This drug is the biggest breakthrough in Melanoma since the current standard of treatment that was first licensed in the 1970's, we are now in 2011 and I struggle to believe that with all the advances in modern medicine we are withholding a drug that has been clinically proven to work.

As Melanoma has one of the fastest rates of increase in the last 25 years, faster than any of the top 10 recognised cancers in the UK, it is my belief that with the increase of Melanoma it is imperative that this drug is available sooner rather than later.

I have also forwarded a copy of this letter I am sending to you to the Secretary of State and the Chair of NICE.

Thank you for your time Mr. Glen, I look forward to hearing from yourself, the Secretary of State and the Chair of NICE in the very near future.

Yours faithfully





cc Prof Sir Mike Rawlins  
Lt Hon Andrew Lansley CBE MP.

COPY

[REDACTED]

18 OCT 2011

Pauline Latham MP  
House of Commons  
London  
SW1A 0AA  
15 October 2011

Dear Ms Latham

I am within your constituency and my sister in law has been diagnosed with malignant melanoma.

Could you please make representations to NICE on my behalf in order to ensure that Yervoy (Ipilimumab) is approved when NICE review it in early November.

My family have been saddened 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 sister in law was diagnosed with malignant melanoma in early September 2011 after being ill for several months and being misdiagnosed with a benign tumour during the late stages of pregnancy. After her son was born she did not improve and her health continued to deteriorate, she was then told that she had late stage melanoma which by this point had spread to her brain, spleen, lungs and liver.

Our family is devastated by this and as you would expect are praying for a miracle, however to have any chance of improvement she needs to have the best medical treatment available including the latest breakthrough treatments in this disease. At this stage we do not know whether Yervoy would help but it is imperative it be available as an option for my sister in law and the thousands of other melanoma patients. She has three young children, the youngest being only 14 weeks old. She should be celebrating the birth of her son but at this point in time she cannot even hold him.

When I look at her I cannot recognise her such is the effect this has had on her in the six weeks since she was diagnosed. She is only 35 years old and should be entitled to anything that could help her keep her precious life and her family keep her with them for longer to enable her to see her children grow and to give them a chance of remembering her.

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

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 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.

I am sending a copy this letter to the Secretary of State and the Chair of NICE.

I you look forward to hearing from you as soon as possible.  
Yours sincerely,

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



[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]  
[REDACTED]

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.

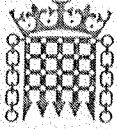
It has been a 30 year wait for any breakthrough in the treatment of melanoma. Ipilimumab is a landmark drug. It is entirely unacceptable that patients and families should have to wait another 3 years for this to be reconsidered particularly considering its use in some areas of England. I believe this 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

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**Julie Elliott M.P.**  
***Sunderland Central***

House of Commons  
London SW1A 0AA

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

28 OCT 2011

Dear Professor Sir Mike Rawlins,

**NICE Technology Appraisal of Yervoy (Ipilimumab)**

I understand that NICE Appraisal Committee A is undertaking a Technology Appraisal for Yervoy (Ipilimumab). Yervoy has been licensed for the treatment of adult patients with metastatic melanoma who have received prior therapy.

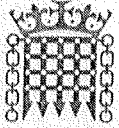
I am disappointed to learn of NICE's recent Appraisal Consultation Document (ACD), which states that access to Yervoy (ipilimumab) has been denied. I would like to seek reassurances that you are taking heed of the messages from patients, clinicians and patient groups and ensure their voices are heard as part of the consultation process.

This decision by NICE is particularly disappointing as this treatment option for people with advanced melanoma is innovative and addresses an unmet need. It is particularly important to emphasise this given that the incidence of melanoma is on the rise – over the last 25 years, in the UK the rate of malignant melanoma has risen faster than any of the top 10 cancers. In addition this aggressive disease disproportionately affects younger people and there is an average 22 years of life lost from each melanoma death – more than many other cancers.

Yervoy (Ipilimumab) is the first licensed treatment in the UK since the introduction of the current standard of treatment in the 1970s.

I urge NICE to look again at its decision and recognise the extent of the huge unmet need in this disease area. There is a danger that if Yervoy is not approved, patients will continue to have limited treatment options beyond the current standard of care.

**Constituency Office**  
**10 Norfolk Street, Sunderland, SR1 1EA**  
**Tel: 0191 565 5327 Fax: 0191 565 9848**



Yours Sincerely,

Julie Elliott

**Constituency Office**  
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HOUSE OF COMMONS  
LONDON SW1A 0AA

24 OCT 2011

Professor Sir Mike Rawlins,  
Chair of NICE

Tuesday, 18 October 2011

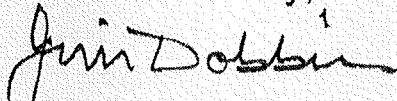
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Dear Professor Rawlins

Re: NICE and Appraisal of Yervoy(Ipilimumab)

I am delighted that the Government is committed to innovations in medicine and was therefore disappointed at the negative appraisal given to the drug Yervoy by NICE. I know that this particular drug could address new treatment for many patients who have little hope of a cure for advanced melanoma. Malignant melanoma has risen faster than any of the top ten cancers and you will be aware there have been no innovations in treatment since the 1970s. Please consider looking again at this decision.

Yours sincerely,

  
Jim Dobbin MP



25 OCT 2011

25<sup>TH</sup> October 2011

Mr David Rutley MP

House of Commons

London

SW1A 0AA

Dear Mr Rutley,

As a constituent of yours in Macclesfield, I am writing a heartfelt plea to ask that you make representations to NICE on my families behalf to ensure that use of the drug Yervoy (Ipilimumab ) is approved when reviewed by NICE in November.

Our family was devastated when last year my husband [REDACTED] was diagnosed with malignant melanoma. He was diagnosed stage 2C and underwent two surgeries to remove his tumor and perform a skin graft. Malignant melanoma kills over 2000 people in the UK each year, with an average of 22 years of more life lost from each melanoma death than many other cancers. Over the last 25 years the rate of malignant melanoma in the UK has risen faster than any of the top cancers in the UK.

We were so disappointed to hear that Yervoy has so far been declined by NICE. Melanoma sufferers have been waiting for three decades for a treatment breakthrough in advanced melanoma. Yervoy has the backing of a number of clinicians and patient groups. [REDACTED] (Christie NHS Foundation Trust) states 'Ipilimumab represents a real advance in the treatment of patients with advanced melanoma. This is the first treatment in the UK to extend patients' life expectancy'. Yervoy is the first treatment to be licensed in the UK which demonstrates an overall survival benefit for people with advanced melanoma. If it is not

available on the NHS, patients will continue to have limited treatment options beyond the current standard of care, first licensed in the 1970's.

[REDACTED] is currently well and is taking part in a clinical trial, having been randomized to the control group. He is monitored every 3 months for signs that his cancer has spread. The 5 year survival statistics for stage 2C malignant melanoma are less than 50%. [REDACTED] is 41 and I am 37 years old. We have 2 beautiful children [REDACTED] 10 and [REDACTED] 8. [REDACTED] is a very keen cyclist and as a family we enjoy walking in the Peak District.

We live in the hope that [REDACTED] will remain well and that he will not develop stage 4 advanced cancer. If Yervoy is not available on the NHS, there are only limited treatment options. I feel it is so important to have access to life extending drugs. Please act now to ensure Yervoy is approved in November and people are given the opportunity to see their children grow, to continue to enjoy their life for as long as possible.

A copy of this letter will also be sent to Andrew Lansley MP, Secretary of State for Health and Professor Sir Mike Rawlins, NICE.

I look forward to hearing from you,

Yours Sincerely

[REDACTED]

[REDACTED]