

**25 June, 2007**

**F.A.O. Andrew Dillon.**

**Dear Sir,**

**I am writing to you as a sufferer of Wet Age Related Macular Degeneration, to protest at the appalling NICE proposals regarding the non use of Macugen and the inhuman limitations on the use of Lucentis.**

**Before you toss my letter on the pile to be shredded, let me briefly state what happened to me.**

**Aged 67, fit, active and fully independent, I awoke one morning and found my vision distorted. Later that same day at the Eye Hospital, after various examinations, an indifferent member of staff said, "Well, you've got Macular Degeneration -nothing we can do about it, so go home and register with the National Association for the Blind !"**

**I stumbled out of the hospital in a state of shock, to return home to tell my equally shocked husband the damning diagnosis. Neither of us had heard of this condition, nor had friends or family.**

**Now, two years later, I am virtually blind in one eye, this eye having deteriorated spectacularly from seeing distorted, wiggly lines to a complete grey/black fog.**

**Without the vision in my other eye (which could "go" at any minute) my life would be reduced to that of a helpless, housebound, dependent old woman. Unable to see to cook, clean, iron, sew, read, shop, drive, garden, watch T.V., write letters, manage my financial affairs, the**

**burden would fall on my rather frail, elderly husband ....  
and, if he were to pass away, the cost of care and support  
services would far outweigh the cost of the denied  
treatment, not to mention the humiliation of dependency.**

**Had I received prompt treatment at the initial diagnosis  
it is quite possible that my sight loss could have been  
arrested - and yet NICE are condemning many thousands  
of resourceful people -who have been the backbone of  
this country and paid their N.I. all their lives- to a blind  
old age by their decision not to treat first eyes.**

**It is as ludicrous as saying, ' don't treat the cancer in the  
left lung/breast, let's wait until it passes to the right one',  
or, ' I'm sorry we can't set your broken right leg until you  
break your left one'.**

**With the drugs available, how can NICE restrict their use?  
One day you, or a member of your family may fall victim  
to this ghastly condition, and first hand experience may  
remind you of the thousands left to suffer following your  
decision.**

**PLEASE ....PLEASE ... MAKE ... THESE... DRUGS.....  
..AVAILABLE.... TO .....EVERYONE.**

**Yours Sincerely ,**

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7, 8, 9, 10, 12, 11  
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95 / 14

folder 7

28<sup>th</sup> June 2007

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

Dear Sir,

I am writing to express my amazement and horror at the release of the recent document about the treatment of Macular Degeneration with the new drugs presently available.

The decision to only use Lucentis in what will amount to only 20% of cases –and then only when the second eye is affected –not to mention dismissing Macugen altogether is absolutely disgraceful.

The name of your organization is a total misnomer as it is absolutely apparent that it does not PURSUE “Clinical Excellence” at all –it simply exists as a means to find an excuse to avoid and evade committing the government to following the wonderful discoveries which medicine is becoming capable of.

Going slowly blind is a frightening disorienting and life limiting experience. It is also, obviously, a terrific blow to the partner of the person involved.

The blindness not only prevents the sufferer from working, driving, reading, following pursuits or even going out alone, it prevents the partner –who has now become the carer from working (and paying taxes) and following his or her individual pursuits which would involve leaving the blinded person on their own for any length of time.

Make no mistake Mr Dillon, just because there is not a total blackness with MD, the sufferer is still incapacitated from doing anything which requires mobility, dexterity, or just the confidence to move forward anywhere but in the home.

If you wear glasses, just try sticking masking tape over the lenses and try making a cup of tea. No matter where you look, you can't look around the blind spots.

I can not understand the short-sightedness (forgive the pun) of the government in not doing it's utmost for the twenty thousand people affected; enabling them to put a halt to the progress of this disease, thus freeing up the NHS from all the follow up procedures entailed in dealing with the aftermath of blindness. Not to mention the Social Services which have to go into overdrive in providing a vast array of facilities, helping the sufferer and their carers to cope.

Then of course there is the attendance allowance paid out to the carers as the sufferer becomes more and more incapacitated. Not to mention the inability, as I have already mentioned, of the carer to hold down a job thus paying into the system instead of drawing from it.

It really is bewildering why you can't take the long term view. However, you have said you are willing to hear from patients and their carers, so taking you at your word I have asked my niece to write this letter to you. I just hope that you will realize that to condemn people to a virtually blind existence when treatment is available to completely change their life prospects is cruel, immoral and frankly foolish.

The money spent on getting many more thousands to stop smoking – taking the long term view of the demands on the Health Service, must be astronomic by comparison, and yet the decision was taken. Doesn't this same thinking apply? Surely you can see the sense in the argument instead of just the cost of the prescription.

Thank you for reading my letter.

Yours Sincerely

[Redacted signature area]

25th June 2007

Dear *M. Dillon,*

I am writing on behalf of my mother, \_\_\_\_\_ who is currently a member of the Macular Degeneration Society. She has recently become almost completely blind through this disease with only a partial and very small residual peripheral vision in one eye which is so indistinct that she can just about see whether it is dark or light.

My mother was widowed in January 2000 and is 85 years of age. She has fairly rapidly succumbed to bi-lateral AMD over the last four years and as well as being blind is also becoming very frail. Initially and at her own expense she has had two sessions of laser treatment ( photodynamic therapy ) in one eye during 2003 which were not successful. Subsequently she has also at her own expense had one lens implant and vitrectomy in the same eye (left side) then later an Avastin injection into her right eye. Sadly neither of these very expensive treatments have been successful.

As a result of the relatively rapid onset of her blindness my mother has now lost most of her independence, confidence, and mobility. Despite the great kindness and support of staff, carers, and her family and friends, upon whom she now totally relies, she can no longer cook, read, watch television, or operate a "talking book" and other modern technology including her radio and telephone without someone else in the room to help her. She cannot leave her flat without assistance and shopping or crossing a road is impossible. Luckily she does have visitors fairly frequently but the majority of her time is spent alone in virtual darkness even though the lights are on.

For Mum most of her daily routine is now a rather lonely, sad and depressing existence for someone who not so long ago was leading such a busy, lively and interesting life. She listens endlessly to the radio waiting for the next visitor, a ring on the door bell, or the next phone call. We strongly feel that this situation was brought about directly as a result of AMD and its debilitating effect. If it cannot be successfully treated at an early stage in both eyes at once it seems pretty certain that it cannot be successfully treated later on as the eyesight deteriorates because of the insidious nature of the disease.

My mother knows that she has been unfortunate most probably due to her age and would of course have done anything she could to save her sight if that had been possible. As with undoubtedly the many thousands of other people of all age groups that are prone to AMD and those who are also suffering from it at the moment, my mother and her family are incredulous that now when new treatments have been found

3, 7, 8, 10, 11, 18a, 19, 22, 28a, 32

to be effective and available it seems that NICE cannot sanction their use by normal prescription under the NHS until the disease has already gone too far in one eye before treatment can be commenced on the second eye to save any sight at all. This is cruel and cynical beyond belief for all of those still suffering the disease. For my mother and many others this treatment has come too late and at great personal and financial cost even though both she and we have been extremely impressed by the professionalism and dedication of the Specialist Consultants who have tried their best to help her.

We personally have no idea of the hidden costs of not dealing with the effects of AMD. Surely, and as with many other treatable diseases, it must be true to say that the real saving in costs of treating this disease effectively now will definitely be far less than the consequential costs of not treating it. It cannot be morally correct to deny treatment when trial results have shown great effectiveness. Any other option will condemn the vast majority of AMD sufferers to live out the rest of their lives in darkness and misery while the politicians and bean counters rattle their money boxes to pay for less deserving causes.

We remain stoic but angry that more positive action seems so very slow in coming.

Yours sincerely



Copy to Tom Bremridge , Chief Executive of The Macular Disease Society.

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

3, 7, 8, 10, 12, 20, 31, 38

408

10<sup>th</sup> July 07

**Mr Andrew Dillon  
Chief Executive  
National Inst for Health & Clinical Excellence  
MidCity Place  
71 High Holborn  
LONDON  
WC1V 6NA**

Dear Andrew

I trust that you will take the time to read this in relation to the concerns being raised over **Age Related Macular Degeneration**.

My mother is eighty- four years of age and lost the sight of her left eye 4 years ago through neglect and inefficiency of the current health service protocol. From the time she had reported to her GP and the referral to an eye Specialist, it was too late to save the sight in this eye.

As a family, we were not aware of this condition until mum's diagnosis, so we became much more vigilant from then, in respect of her right eyesight.

At the first indication of deterioration in the right eye we arranged a consultation with both her optician and an eye specialist. With no appropriate offer of help, mum was referred onward to a Professor in the [redacted] Hospital,

Once again the timing was paramount and if mum had been seen in time, they may have been able to save the right eyesight through the use of the treatment that you now seek to restrict on the NHS.

I am the primary carer for both my parents, my dad turns ninety- four this month, and and both of them are devoted to each other and their family. Thankfully both of them still possess excellent mental faculties, but my mum is severely limited in her mobility due to personal safety concerns, and this worries both of them.

I attend hospital appointments with both of them and it grieves me deeply to observe the many ailments and conditions that the elderly have to suffer, and the loss of sight is particularly upsetting.

I sometimes wonder if decision makers such as yourself actually understand what it is to be robbed of your eyesight and your independence as a result of such a disease.

My mum can no longer enjoy the garden that she derived so much joy from in recent years, she cannot appreciate the cards and pictures that her grandchildren make for her, she cannot witness their physical development, she can't sign Birthday and Christmas cards anymore for the family. It's no longer a case of what she can do in her golden years, but what she can't.

I have to supervise every individual tablet she takes, aside from all the other limitations she now endures as a result of her sight loss. It upsets both me and my siblings and in fact it has altered the emotional status of the entire family circle.

My father served his country in World War 2, was wounded and endured suffering in a German prisoner of war camp for a prolonged period, and he continues to suffer years on in 2007 watching my mum's battle with everyday living and missing out on the little things that gave her life some degree of quality.

As a devoted son I am angered that the British Government would have deemed my mum unsuitable for basic treatment that would have saved her eyesight. For a meagre sum of money they have effectively robbed her of her independence. Her only hope now is that we can try and fund raise some money to pay for an injection that could provide her with some partial vision in her right eye only, but it is extremely expensive, and once again limited in availability.

I am disgusted and outraged that Policy can determine whom the Government can inflict this suffering upon, it is deliberate cruelty in my opinion. I seek answers why this treatment is freely available in other parts of the UK, and please remind me what 'UNITED' actually represents, because it obviously isn't Government regulations.

I am lending my support to the RNIB in their campaign to reverse this absurd decision and can only hope and pray that one individual such as yourself will hear the plea, and work tirelessly to help those whose sight can be saved with the availability of these drugs.

**PLEASE HELP US ANDREW DILLON, PLEASE!!!!**

Yours sincerely



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15  
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7/14 Filder (9)

By post, fax & e-mail (nice@nice.org.uk)

28<sup>th</sup> June 2007

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

Dear Sirs,

**Re: NICE – Treatments for Wet AMD**

I was quite appalled to hear the approach NICE are taking towards treatment for wet AMD, but can now understand the treatment I have received (or more importantly not received) from those I have looked to for help. I am a sufferer myself, & would like to share my feelings & opinions with you, & my sense of burden on others around me.

I have always been quite independent, having a career in my earlier days before raising two boys that I am now immensely proud of. I have always encouraged them to study hard at school, get good jobs & raise their own families without needing help from others. Whilst we have all paid our taxes & national insurance, none of us have ever had to seek or rely on benefits from the State. It is only now in my more senior years that I need to turn to the NHS for help, & can honestly say that I expected to get it.

When I first started suffering with Wet AMD, I felt quite frightened. I didn't understand why quite suddenly my sight was failing, & why to such a degree. The sight in my one eye had deteriorated to some degree before I consulted my doctor. I thought it might have been an infection & would clear up. Then my second eye started to deteriorate.

The effect it has had on my life has been quite dramatic. I can't read or write which is a problem, particularly with signing paperwork. I have to rely on others to read to me & tell me it's okay to sign documents, cheques etc. Much of the things I enjoyed in life are now lost to me, even simple things like watching television, sewing & doing jigsaws which I have enjoyed for many years.

I can't do my make-up or hair now without the help of others. Tasks I have always done around the house for my family such as cooking, washing, ironing need to be done by my husband, & I thank my lucky stars he is still with me, as it doesn't bear thinking about how I would cope without him.

He takes me shopping, as I can't see products in a supermarket. I can't carry money, as I can't see clearly what I am handing over.

I had been helping to look after my sister-in-law as she has diabetes & can't get about to do her own shopping. This is now another burden for my husband to do alone.

When I have been shopping with my husband, I have problems seeing steps & escalators clearly. I even walked into a glass window at the front of a shop thinking it was an opening.

I feel a complete burden on those around me, where I was once the one looking after them. What on earth would I do without my husband? I would certainly cost the State a lot more than the cost of this treatment. I can't understand how you can honestly believe this is a cost effective decision, or that it is fair on sufferers like myself, or on those that now have to care for us.

Do you really believe it is fair to take taxes from us all our working lives, & give nothing back when we need it? Do you not think we are entitled to a reasonable quality of life? I know I will not get my full sight back, but surely where treatment is available as it is here, I should be allowed at least a chance for it to improve or stabilise. Even to retain the limited sight I have now would be better than losing it altogether.

Knowing the treatment is available but untouchable is heartbreaking. Maybe people will opt to move to Scotland where they clearly value giving people a quality of life.

I'm glad my boys weren't brought up to make such heartless decisions as you believe are justified here.

Yours Faithfully



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61/4A - folder (9)

29 June 2007

The Chief Executive  
National Institute for Health and Clinical Excellence  
71 High Holborn  
LONDON WC1V 6NA

Dear Mr Dillon

I very much hope this letter will reach you personally. I am aged 73 and have lost most of the sight of one eye from wet macular degeneration. If the other eye undergoes similar degeneration I shall be unable to read, or watch tv, or drive, or indeed to recognise people's faces. I shall be unable to look after my husband, who has a cardiac condition, if in time he needs to depend on me for everyday care.

I am therefore very concerned to learn that NICE has prepared a consultation document which proposes to restrict the use of the most promising modern treatments for wet AMD. I am horrified to learn that macugen (which has been shown to be effective when used in conjunction with lucentis) is to be withheld completely, and that lucentis is to be withheld if only one eye is affected.

Wet AMD generally affects both eyes, but it usually commences in only one eye before subsequently affecting the other. It is therefore essential that immediate treatment should be available as soon as AMD is diagnosed, even if (as will be the case initially) only one eye is affected.

I also understand that lucentis will not be available except for cases of classic wet AMD, even though the majority of sufferers commence with occult wet AMD.

I speak from experience when I tell you that AMD develops very swiftly, and needs urgent treatment at the earliest possible moment. If your Institute's proposals become policy, they will condemn many people to virtual blindness. This will have a terrible personal cost, and in time lead to heavy demands on the NHS and social services when sufferers, many of whom will also be carers, can no longer cope with everyday living.

I therefore wish to urge you and your colleagues to reconsider these proposals from NICE as a matter of the highest priority. The cavalier attitude adopted towards the many unfortunate sufferers whose first eye is losing its sight, and who are liable to be cast aside by the NHS as not meriting any treatment, is completely at odds with the whole ethos of a health service. If I may say so, such proposals are a disgrace to a civilised country.

Yours sincerely

3, 16, 26, (38), (34)

(1)

Date: Saturday, 23 June 2007

Dear Mr. Dillon,

### Treatments for "Wet" AMD

My wife and I are alarmed and appalled by the recommendations of your Preliminary Report

At beginning of the year my wife was diagnosed with "Wet" Macular Degeneration in her right eye and a suggestion of the disease in the left eye. At that time I was confronted with an unpleasant dilemma. Our local PCT would not fund the Lucentis treatment recommended by her consultant but there was the possibility of private treatment at a cost of £1600's per injection. She would need at least three injections to assess the drug's effectiveness. We had some savings so we decided to go private rather than allow the degeneration to continue.

She has now had the three injections and the treatment would appear to be effective. The consultant is suggesting that further injections are needed and, judging from his remarks, the total cost might be in excess of £30,000's. Our meagre savings are almost depleted. What are we to do?

Some fifty odd years ago I risked my life for this country - in Korea. Since then, I estimate that my wife and I have contributed something in excess of £200,000s, to the NHS, through direct taxation. Fortunately, we have not required any major medical treatment during that time - but now we do! Is it possible that the Nation, and the NHS, with your connivance, will fail us in our need?

If my wife should lose her sight, I can probably manage for a couple of years but after that we shall need considerable support from Social Services. I don't know what type of AMD she has but it is unlikely that she falls within the 20% with "classic" lesions. If this Lucentis treatment is not funded, my wife and I will find it impossible to cover the cost of any further treatment.

Yours Sincerely,

Andrew Dillon Chief Executive NICE

7,8,11,13

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28<sup>th</sup> June, 2007

Dear Mr Dillon,

My mother asked that I type the enclosed letter for you. However I thought it would have more meaning if you received her own handwritten copy. Hence the enclosed letter.

I have put this covering note purely to ensure that you have her home address.

I would however echo her sentiments but also add my own view as a sporadic carer of two parents who both have macular degeneration. Surely it makes no sense to allow someone's sight to deteriorate in both eyes before they become eligible for treatment. The cause seems somewhat lost then.

I would be grateful for your consideration of the issues raised in both letters.

Yours sincerely

[Redacted signature area]

Dear Mr Dillon,  
I am writing this  
letter in response to  
NICE's finding in regard  
to the drugs metuGen  
& Lucentis.

I have ARM D in both  
eyes + I am the carer  
in this household. My  
husband has heart

problems, osteoporosis  
of the spine, Diabetes

+ has recently been

diagnosed with ARMD.

Consequently neither

of us can read or drive

mobility + independence

are severely curtailed.

We are more prone  
to accidents in the

home - ie burns + falls.

so becoming a

heavier burden on

our busy families.

To be denied treatment  
with Lucentis that

could improve vision

+ quality of life is

a great blow to many

thousands of MD. Sufferers.

Yano 5 weekly



As a sufferer from AMD/Glaucoma and Diabetes, I am writing to express my very deep concern (outrage would perhaps be a more appropriate word) at the severe limits which NICE is considering in the availability of effective treatments for AMD.

Such an approach by NICE would condemn me to blindness. Since I am war deafened as a result of Military Service I will be effectively rendered Blind Deaf by this approach, -too horrible a fate to contemplate. Ironk therefore that my hearing loss as an Army veteran was incurred in defending the very Nation which appears prepared to calmly discount the importance of sight for myself and thousands of others.

A further twist to this story is that at seventy-one years of age I am otherwise quite fit and care for my wife who suffers from a different but very serious set of health problems. If I am to lose my sight, I would be unable to care for my wife and additionally we both would require a raft of physical, social, financial and medical support quite a significant cost to Society, not to mention the anguish to my wife and I and our family.

Treatments for AMD

Dear Mr. Dillon,

28<sup>th</sup> JUNE 2007

71 High Holborn,  
 Middy Place,  
 London WC1V 6NA

Andrew Dillon,  
 Chief Executive,  
 National Centre for Health and Clinical Excellence.

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 97/14/12



Yours sincerely

I urge your IMPLEOR you to consider the humanitarian injustice, the social and yes financial implications which restricting AMPD treatments would incur for peoples like us and for the Nation at large.

Your proposals would effectively render such assurances as a meaningless gesture.

Indeed as a veteran I am assured by the Government of priority medical help.

obligations to Society.  
through taxation and devotion to the Community our legal and moral six grandchildren. Served our Nation in war and peace and diligently paid which we were born we have struggled to raise three fine children, and now My wife and I have been hardworking, honest citizens of this country. in