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@ 25 June, 2007

F.A.O. Andrew Dlllon.
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Dear Sir,
I am writing to you as a sufferer of Wet Age
Related MacularDegeneration, to protest at the appalling NICEproposalsregarding the non use of Macugenand the inhuman limitations on the use of Lucentis.

Before you toss my letter on the pile to be shredded, let

me brieflystate what happened to me. ..
Aged 67, fit, active and fullyindependent, I awoke one morning and found my vision distorted. Later that same day at the EyeHospital,after various examinations, an indifferent member of staff said, "Well,you've got MacularDegeneration -nothing we can do about it, so go home and register with the NationalAssociationfor 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, wlggley lines to a complete grey I black fog.

Without the vision Inmy 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, dean, iron,sew, read, shop, drive, garden, watch T.V.,write letters, manage my finanda' 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 ofthe denied treatment, not to mention the humiliationof dependency.

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

It is as ludicrousas saying, ' don't treat the cancer in the left lung/~reast, 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 YOUI:left one'.

Withthe drugs available, how can NICErestrict their use? One day you, or a member of yourfamilymay fall victim to this ghastly condition, and first hand experience may

remind you of the thousands left to suffer followingyour decision.
PLEASE PLEASE... MAKE... THESE... DRUGS...... ..AVAILABLE TO EVERYONE.

Yours Sincerely,

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28th June2007
Andrew Dillon
Chief Executive
National Institute for Health and Clinical Excellence

71 High Holbom
London WCIV 6NA

Dear Sir,
I am writing to express my amazement and honor at the release of the recent document about the treatment of Macular Degeneration with the new drogs presently aVailable.

The decision to only use Lucentis in what will amount to only 200,1,of cases -and then only when.the second eye is affected -Dot 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.

Goingslowlyblindis a frighteningdisorientingand lifelimitingexperience. It is also, obviously,a terrificblowto thepartnerof the personinvolved.
The blindnessnotonlypreventsthe sufferer&omworking,driving,reading,following pursuitsor evengoingout alone,it preventsthe partner-who hasnowbecomethe carer &omworking(andpayingtaxes)and following his or herindividualpursuitswhich would involveleavingthe blindedpersonon their ownforany lengthoftime.

Make no mistake Mr DiIlon,just because there is not a totaI blackness with MD, the sufferer is still incapacitated &omdoing 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 pUta halt to the progress of this disease, thus fteeing up the NHS ftom 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.

1ben of course there is the attendance aUowance 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 ftom it.

It reallyis bewilderingwhyyoucan't take the longtermview. However,youhave said you are willingto hearftompatientsandtheir carers,sotakingyou at yourwordI have askedmy nieceto writethis letterto you.Ijust hopethatyouwiltrealizethat to condCm peopleto a virtuallyblindexistencewhen treatmentis availableto cOmpletelychange their lifeprospectsis cruel,immoraland ftankly foolish.
1be money 8pCRtODgettktg II81Y more thousands to stop smoking -taking the long term view ofthe dem8ndson theHealthService,mustbe astronomicby comparison,andyet the decisionwu t8bn. Doesn'tthissamethinIdnaapply? Surelyyoucan see the sense inthe-ar2Umentinsteadofjust-theeostof the pmc;ription.

Thank you for reading my letter.

Yours Sincerely

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25th June 2007

Dear /vv ~/

Iamwritingonbehalfofmymother,- - . whoiscurrentlya memberof the Macular Degeneration Society. She has reeeritlybecome 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-IateralAMDover the last four years and as well as being blind is also becoming very.frail. Initiallyand 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 alSOat her own expense had one lens implant and vitrectomy in the same eye (leftside) 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 familyand friends, upon whom she now totally relies, she can no longer cook, read, watch television, or operate a "tatkingbook- and other modem 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 roadeis impossible. Luckilyshe does have visitors fairlyfrequently 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, livelyand 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. Ifit cannot be succeSsfully treated at an early stage in both eyes at once itseems pretty certain that it cannot be successfully treated later on as the eyesight deteriorates because of the insidious nature of the disease.

Mymother 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 ifthat had been possible. As with undoubtedly the many thousands of other people of all age groups that are prone to AMDand 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

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to be effective and available itseems that NICEcannot sanction their use by normal prescriptionunderthe NHSuntilthe diseasehas alreadygonetoo far in one eye beforetreatmentcan be commencedon the secondeyetosave anysightat all.Thisis cruel and cynical beyond belieffor all of those stillsuffering 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 heJpher. ..
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We personally have no idea of the hidden costs of not dealing with the effects of ADM. Surely,and as with manyothertreatablediseases,it mustbetrue to saythat the real saving incosts oftreatingthis diseaseeffectivelynowwill defjnitelybefar less thanthe consequential costs of not treating it. It cannot be morally correct to d~ny 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 ~ng!y tl:tat mo~ RQ!it!'leJ:~~Qn~m_~ so very ~lQWin_!X>ming.

Yours sincerely

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

To -Andrew Diflon, Chief Executive,
National Institute for Health and Clinical Excellence

MidCityPlace .
71 High Holbom
London
WC1V 6NA

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IOU!July 07
Mr Andnw DiUOD
Chief EIecutiW
National IDIt for Health & CliDiealEIeellence

MidOty Place
711fi&b Bolbom
LONDON
WCIV 6NA

Dear Andrew

I trust that you will take the time to read this in relation to the concerns being raised overAae RelatedMaaJlar DeaeaeratiOD. .
My mother is eighty-four years of age and lost the sight of her left eye 4 years ago through neglect and inefficiencyof the current health service protocol. From the time she had reported to herOP 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 Wlti1mum's diagnosis, so we became much more vigilantfrom then, in respect of her right eyesight.
At the first indicationof deterioration in the right eye we arranged a consultation with both her optician and an eye specialist. With no appropriate offer of helD,mum was referred onward to a Professorin the!- '.,Hospital,.
Once againthe timingwas paramolDlt8nd if muin had beenseenin time,theymay have been able to savethe righteyesightthroughthe use of the treatmentthat you nowseekto restrictontheNHS.

I am the priInmy 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 excellentmentalfaculties, but my mum is severelylimited in her mobility du~ to personal safetyconcerns,and this worries both of thetD.
I attend hospital appointmentswith both of them and it grievesme deeply to observe the many ailments and conditionsthat the elderly have to suffer, and the loss of sight is particularly upsetting.

I sometimes wonder if decisionmakers such as yourself actuallyunderstand what it is to be robbed ofyoW'eyesightand your independence as a result of such a disease. My mum can DOlonger 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 caonot witness their physical development, she can't sign Birthday Slid Christmas cards anymore for the family. It's no longer a case of what she can do in her golden years, but whatshe can't.

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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 alteredthe emotionalstatus of the entirefamilycircle.
My father served his country in World War 2, was wounded and endured sufferingin a German prisoner of war camp for a prolonged period, and he continuesto suffer years on in 2007 watchingmy mum's battle with everydaylivingand missingout o~ the little thingsthat gaveher life some degree of quality.

As a devoted son I am angered that the British Government would have deenied my mum unsuitable for basic treatment that would have saved her eyesight For a meagre sum of money they have effectivelyrobbed her of her independence.Her only hope now is that we can try and fund raise some money to pay for an injectionthat could provide her with some partial vision in her right eye only, but it is extremely expensiv~ and Onceagainlimited in availability.
I am disgusted and ou1ragedthat Policy can determine whom the Government can inflict this suffering upon, it is deliberate cruelty in my opinion. I seek answers why this treatnxmt is free1yavailablein other parts of the UK, and please remind me what 'UNITED' actuallyrepresents,because it obviouslyisn't Governmentregulations.

I am'lending my support to 1heRNIBin their campaign to reversethis absurd decision and can onlyhope and pray that one individualsudt as yourselfwill hearthe plea, and work tirelessly to help those whose sight can be saved with the availability of these drup.
PLEASE HELP US ANDREW DILLON, PLEASE!!!!

Yours sincerely

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

28111June 2007
Mr Andrew Dillon
Chief Executive
National Institute for Health & Clinical Excellence

MidCity Place
71 High Ho/born
London
WC1V 6NA

DearSirs,

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 ~ailing,& 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 Ihave 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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29 June 2007

The ChiefExecutive
NationalInstitute for Healthand ClinicalExcel1ence

71 HighHolbom
LONDON WClV 6NA

Dear Mr Dillon

I very much hope thisletter willreach you personally.I amaged 73 and have lost most of the sight of one eye from wet macular degeneration.If the other eye undergoes similar degenerationI shall be unable to read, or watch tv, or drive, or indeed to recognisepeople'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 everydaycare.

I am therefore very concerned to learn that NICE has prepared a consultation document which proposesto restrictthe use of the most promisingmodem treatmentsfor wet AMD. I am horrified to learn that macugen (which has been shown to be effective when used in conjunction with lucentis)isto be withheldcompletely,and that lucentisisto be withheld if only one eye is affected.

Wet AMD generally affects both eyes, but it usually commences in only one eye before sub~ently 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 thoughthemajorityofsuffererscommencewithoccultwetAMD. '

I speak from experience when I tell you that AMD develops very swiftly, and needs urgent treatment at the earliest possible moment..1f your Institute's proposals become policy, they will condemnmany peopleto virtual blindness.This will have a temole 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 longercope with everyday living.

I therefore wish to urge you and your colleaguesto reconsiderthese proposals from NICE as a matter of the highestpriority.The cavalier attitude adoptedtowardsthe many unfortunatesufferers whose first eye is losing its sight, and who are liable to be cast aSideby the NHS as not meriting any treatment,is completelyat odds with the whole ethos of a health service.If I may say so, such proposals are a disgraceto a civilised country.

Yourssincerelv

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Dale: Saturday,23June2007

Dear Mr. Dillon,

Treatments for.Wer AMD

Mywife and I are alanned and appalled by the recommendations of your
Preliminary Report

At beginning of the year my wifewas diagnosed with "Wer Macular
Degeneration in her right eye and a suggestion of the disease in the left eye. At that
time Iwas confronted with an unpleasant dilemma. Our local PCT would not fund the ~LUMntiureatment recommended by her consultant but there was the possibilityof
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.

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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 £3O,OOO'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,Ooos, to the NHS, through direct taxation. Fortunately, we have not required any major medicaltreatment duringthat time - but nowwe dol Is itpossible that the Nation,and the NHS, with your connivance, willfail us in our need?

Ifmy 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. Idon't
- know what type of AMD she has but it is unlikely that she falls within the 20% with -classic' lesions. Ifthis Lucentis treatment is not funded, my wife and Iwillfind it impossible to cover the cost of any further treatment.

yours Sincerely,

AndrewDillon ChiefExecutive NICE

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28th June, 2007

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Dear Mr Dillon,

Mymother asked that Itype the enclosed letter for you. However Ithought it would havemore meaningifyou received her own handwritten copy. Hence the enclosed letter.

I have put this coveringnote pur~IY1(H~[JlYnU"atYQPhave her home address.
I

I would however echo her sentiments but also add myown viewas a sporadic carer of two parents who both havemaculardegeneration. Surelyit makes no sense to allowsomeone's sightto deteriorate in both eyes before they become eligiblefor treatment. The cause seems somewhat lost then.

I would be gratefulfor your consideration of the issuesraised in both letters.

Yourssincerely

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