Asthma (severe, persistent, patients aged 6+, adults) omalizumab (rev TA133, TA201): appraisal consultation document

**Response from Asthma UK** 

'Xolair totally changed my life. The thought of a life changing treatment not being available to anyone who needs it is appalling. It is only given as a last resort anyway, so considering reducing prescribing it is ridiculous. Not being able to breathe, being so restricted in your everyday life, and then dependant on oral steroids that will affect your health in so many ways is a difficult way to live, and my heart goes out to anyone, especially children with their lives ahead of them, who is coping with this.'

This submission has the support of:

Primary Care Respiratory Society UK

Association of Respiratory Nurse Specialists

### Introduction

Asthma UK is pleased to have the opportunity to respond to the consultation document and evaluation report. Our response includes a small selection of the dozens of views that have been shared with us by people with asthma and their families since the consultation was launched (a comprehensive set of comments is included as an appendix).

The people who would typically be treated with omalizumab in the UK are seriously ill because of their asthma. We know from the APEX study,<sup>1</sup> from clinical experts and most importantly from patient experience that many of them have frequent severe asthma attacks and almost constant breathlessness which makes it impossible for them to do things that other people take for granted. They also suffer terrible side effects from treatments which they have felt compelled to take for years because there was no more effective alternative until omalizumab became available. Denying access to omalizumab now will lead to a lot of unnecessary suffering among a small group of people who are very severely affected by asthma.

# On behalf of these people, Asthma UK would like to see a positive recommendation for omalizumab in a subgroup of patients aged 6 and above who are on maintenance or frequent courses of oral corticosteroids.

We would like to draw the committee's attention to three key issues which are of concern to patients before moving on to address the consultation questions where we elaborate in more detail. These are:

A. Change of recommendation in the absence of significant new evidence.

People with asthma, especially those who currently benefit from omalizumab, find it difficult to understand the rationale for reversing NICE's previous recommendation in favour of omalizumab for adults (TA 133). In 2010, NICE published an explanation that it had recommended omalizumab despite a cost per QALY of >£30,000 because of the severity of the illness, the strength of stakeholder feeling and the degree of innovation from the treatment.<sup>ii</sup> All of these circumstances remain unchanged; severe

'It's amazing, I started 6 years ago and it totally changed my life around, I was told there was nothing more they could do and was basically going to die, then I started this and I'm here today living a life. It's so sad for people in the position I was in as it could be their last life line.'

asthma remains a very serious condition, people with asthma very much want omalizumab to remain available and there are no other options for many of the people who use it.

Neither has there been significant change in the evidence of effectiveness of omalizumab. Instead, the main change in cost-effectiveness estimates has been driven by the use of different mortality rates in the model. The committee has acknowledged that there are flaws with both available estimates of asthma mortality<sup>iii</sup>, so Asthma UK does not feel that it is fair to patients to move towards using a mortality estimate which generates a higher ICER.

'Xolair has saved my son's life. He is stage 5 and very severe - he's been using singular for years. I will be very concerned if it's stopped as we've been told by doctors his asthma will kill him.'

### B. Inadequate consideration of the side-effects of oral corticosteroids

Side effects of oral corticosteroids are frequently described by people with severe asthma as one of the worst things about their condition, and we know that omalizumab can help to reduce the need for long-term high doses of these treatments.

Asthma UK respects the efforts made by the Committee to take the impact of these side-effects into account and recognises that the evidence that was presented had some limitations. However, we do not agree with the Committee's judgment that it is implausible for the unquantified adverse effects to exceed the quantified adverse effects<sup>iv</sup>. The unquantified effects

'As a severe asthmatic - I've relied HEAVILY on Xolair since 2007 - when it gave me my life back. Although my asthma is still classed as severe - it certainly helped me - and I doubt I would still be here without it. I worry that it will be withdrawn from me - and I will have to rely on steroids even more than I do now - which is a terrifying concept - with all the side effects. In my view - this is just a cost cutting exercise, but sadly it's hitting the most vulnerable the chronically sick."

are among those most commonly reported by patients as having a major impact on their quality of life and there is published evidence of significant DALY losses and NHS costs from these conditions in the general population. We therefore feel it is highly plausible that these adverse effects would be enough to bring the ICER below NICE's informal £30,000 threshold.

### C. Lack of consideration of family and carer benefits

People with severe asthma and parents of children with severe asthma often tell us about the impact of the condition on family life and on the health and wellbeing of the family members who are indirectly affected. Asthma UK was therefore disappointed that no attempt was made to quantify the health and personal social services impact of omalizumab on the families and carers of people who are taking it. This could have had a favourable impact on the ICER.

## **Consultation questions**

## 1. Has all of the relevant evidence been taken into account?

No. From the patient perspective, there are two major gaps in the evidence that has been considered. These are evidence of side effects of oral corticosteroids and evidence of family and carer benefits.

In addition, it is important to note that there is evidence from patients of some important benefits which fall outside NICE's usual scope for consideration. For example, many people with severe asthma have been able to return to work or education as a result of this treatment.

### 1.1 Evidence of the impact of side effects from oral corticosteroids

The strength of feeling among people with asthma about the negative impact of long-term, high-dose oral corticosteroids cannot be exaggerated. NHS Evidence-accredited asthma guidelines state that 'patients on long term steroid tablets... or requiring frequent courses of steroid tablets (eg three to four per year) will be at risk of systemic side effects'.<sup>v</sup> This is also widely recognised by clinicians, but many of the adverse effects - even those which are well-evidenced in the literature - have not been fully taken into account.

'I think NICE just does not realise what difference it makes talking Xolair instead of high level steroids. They may think its not cost effective - but that is looking at it very short sightedly! They are not considering the fact that Xolair patients are usually able to "contribute to society" as they are able to work, look after their families and live pretty normal lives ...whereas life on high level steroids is everything but normal. Apart from dealing with the "soft" side effects (hair loss, weight gain, thin skin) there are also heavy long term issues - like heart disease and osteoporosis, etc to look at this is not taking in to consideration that one is feeling "poorly" most of the time and is not able do as much as one likes or wishes.'

There is good evidence that the side effects of oral corticosteroids include mental health impacts, obesity, skin problems and many other conditions (listed in Table 1) which have not been incorporated into the cost-effectiveness model used in this appraisal. Many of these side effects from systemic corticosteroids are in areas which lead to major public health concern, significant utility losses and high financial cost to the NHS - particularly obesity and mental illness (including depression and anxiety).<sup>vi vii vii</sup> We feel that evidence in this area has not been adequately considered.

1.2 Evidence of the impact of severe asthma on family and carers and of potential benefits of omalizumab in reducing this

'My son is a severe asthmatic not well controlled and had been told he would have to wait until he was at least 12 to get it (he's 9). This is really bad news for us. It seems severe asthma is seen as very low priority, despite the fact it has such a devastating effect the quality of life of the asthmatic and their family. Most people perceive it as being a bit wheezy. They should spend a week in the life of an asthmatic and see something as basic as breathing is so hard.'

Unfortunately, severe asthma affects entire families, not just the person who is ill. In particular, childhood severe asthma can have a very important impact on parents. Qualitative research and the stories of people in contact with Asthma UK demonstrate a pervasive impact of childhood asthma on daily life, with significant emotional burdens for those affected.<sup>ix x</sup> Parents - particularly mothers - are more likely to suffer from depression if their child has asthma - and the severity of a child's asthma symptoms is also associated with the likelihood of maternal depression. A US study found that mothers of children with persistent asthma were 2.77 times as likely to have depression as the mothers of those with intermittent asthma. <sup>xi,xii</sup> Asthma symptom persistence and severity also has a more general impact on parental quality of life, impacting both emotional function and activity limitation.<sup>xiii xiv xv</sup> This suggests that successful treatment to reduce asthma symptoms should have an important impact on quality of life. Omalizumab does this; the committee has already heard from a patient expert about the benefits that it can have for a family. While it may not have been possible to quantify this impact in the cost-effectiveness model, we would urge that it ought to be taken into consideration as a special factor.

# 2. Are the summaries of clinical and cost effectiveness reasonable interpretations of the evidence?

Not entirely. The threshold analysis conducted for the appraisal by the assessment group found that between 47% and 58% of the negative health consequences of oral steroids would need to have been unquantified in the cost-effectiveness model in order for omalizumab to be cost-effective at £30,000 per QALY (ie that the unquantified consequences would need to be between 0.9 and 1.4 times the quantified consequences). The Committee judged that this was not plausible. Based on what patients say to Asthma UK, we strongly disagree.

Table 1 identifies side effects of oral steroids that are reported by patients to Asthma UK and which of these side effects have been incorporated into to the costeffectiveness model that was presented to the committee. Of the 16 people who we interviewed for our initial submission to the committee, all had taken oral steroids either as maintenance medication or for multiple short bursts and 14 of them reported side effects without prompting.

Many commonly-reported side-effects have not been included in the costeffectiveness model, including some of those which have been recognised in systematic reviews of literature and which patients feel have a very significant impact on their quality of life. Mental health problems and weight gain are the side effects which are most often highlighted by people with asthma as having a significant impact on their quality of life; neither of these is considered in the costeffectiveness analysis, which leads us to believe that the quantified adverse effects of oral corticosteroids are a serious underestimate of their overall impact on patients.

Side effect	Ever reported by patients to Asthma UK?	Number of times reported by patients interviewed for current MTA (n=16)	Recognised in systematic review of literature <sup>xvi</sup>	Included in cost- effectiveness analysis
Fracture/osteo porosis	Yes	5	Yes	Yes
Diabetes	Yes -reported in 2010	0	Yes	Yes
Peptic ulcer	No	0	Yes	Yes

### Table 1: side effects of oral corticosteroids

Side effect	Ever reported by patients to Asthma UK?	Number of times reported by patients interviewed for current MTA (n=16)	Recognised in systematic review of literature <sup>xvi</sup>	Included in cost- effectiveness analysis
Stroke	No (though weight gain and increased blood pressure are reported)	0	Yes	Yes
Cataract	Yes	1	Yes	Yes
Myocardial infarction	No (though weight gain and increased blood pressure are reported)	0	Yes	Yes
Glaucoma	No	0	Yes	Yes
Non-Hodgkin's Iymphoma	No	0	Yes	Yes (but the analysis did not include NHS costs saved, only QALYs gained)
Sleep disturbance	Yes	5	Yes	Yes (but the analysis did not include NHS costs saved, only QALYs gained)
Adrenal insufficiency	Yes	2	Yes	Yes (but the analysis did not include NHS costs saved, only QALYs gained)
Mental health problems (categorised in assessment report as 'mood disturbance')	Yes - depression, anxiety, aggression and one case of psychosis	9	Yes	No
Weight gain	Yes - and patients also mention this worsening other conditions such as sleep	9	Yes	No

Side effect	Ever reported by patients to Asthma UK?	Number of times reported by patients interviewed for current MTA (n=16)	Recognised in systematic review of literature <sup>xvi</sup>	Included in cost- effectiveness analysis
	apnoea			
Abnormal hair loss/growth	Yes - reported in 2010	0	Yes	No
Skin conditions	Yes - reported in 2010	0	Yes	No
Lethargy/weak ness	Yes	1	Yes	No
Pain	Yes	2	Yes	No
'Moon face' or Cushing's Syndrome	Yes	2	Yes	No
Headaches/mi graines	Yes	2	Yes	No
Reflux	Yes	2	Yes	No
Growth impairment	Yes - reported in 2010	0	Yes in children	No
Nausea/vomiti ng	Yes	2	Yes in children	No
Menstrual problems	Yes	1	Yes, but low quality study	No
Oral thrush	Yes - reported in 2010	0	No	No
Dental problems	Yes - reported in 2010	0	No	No
Carpal Tunnel Syndrome	Yes	1	No	No
Hot flushes	Yes	1	No	No
Tremors and palpitations	Yes	1	No	No
Liver damage	Yes	1	No	No

# 3. Are the provisional recommendations sound and a suitable basis for guidance to the NHS?

No. Asthma UK would like to see a positive recommendation for omalizumab in a subgroup of patients aged 6 and above who are on maintenance or frequent courses of oral corticosteroids.

Omalizumab is an innovative treatment for a serious condition – indeed, it is the only treatment that has succeeded for some people who are so severely affected by their asthma that they would otherwise be virtually housebound. We strongly urge the Committee to reconsider its recommendation for this small subgroup of patients. Making it treatment available to these people under specialist supervision would be a pragmatic approach which ensures access to an important treatment while limiting the total financial burden on the NHS.

'My 11 year old just [read] a newspaper article about this and burst into tears. She is on week 9 of a 16 week trial for Xolair and she has been able to do PE for the first time in 2 years. She has also not had any hospital admissions since being on it which is a miracle. She still suffers some symptoms but not nearly as bad as she was.'

viii Mann R, Gilbody S, Richards D. (2009). Putting the 'Q' in depression QALYs: a comparison of utility measurement using EQ-5D and SF-6D health related quality of life measures. Social Psychiatry and Psychiatric Epidemiology 44(7):569-78.

ix Yawn, B, The impact of childhood asthma on daily life of the family - a qualitative study using recurrent thematic analysis, PCRJ, 2003 12(3): 82-85

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xiii Cerdan N et al, Asthma severity in children and the quality of life of their parents, Applied Nursing Research, 25 (2012) 131-137

i Barnes N, Mansur A, Menzies-Gow A, Radwan A, 2012, The APEX study: A retrospective review of outcomes in patients with severe allergic asthma who were or were not hospitalised in the year prior to omalizumab initiation in UK clinical practice, ERS Annual Congress

ii Rawlins M, Barnett D and Stevens A, 2010, Pharmacoeconomics: NICE's approach to decision-making, British Journal of Clinical Pharmacology 70: 3, 346- 349

iii NICE, 2012, Appraisal Consultation Document Asthma (severe, persistent, patients aged 6+, adults) - omalizumab (rev TA133, TA201): appraisal consultation document, pp46-47 [elsewhere: ACD]

iv ACD, p 51

v BTS/SIGN British Guideline on the Management of Asthma. 101

vi Maheswaran H, Petrou S, Rees K and Stranges S, 2012, Estimating EQ-5D utility values for major health behavioural risk factors in England. Journal of Epidemiology and Community Health. 9pp

viiThomas C and Morris S, Cost of depression among adults in England in 2000 The British Journal of Psychiatry (2003) 183: 514-519

xi, Leticia L Leao, MD et al. High Prevalence of Depression amongst Mothers of Children with Asthma. Journal of Asthma.2009

xii Madeleine U Shalowitz et al. A Community-Based Study of Maternal Mental health, Life Stressors, Social Support, and Children's Asthma, Pediatrics. 2006.

xiv Halterman J et al, The Impact of Childhood Asthma on Parental Quality of Life, Journal of Asthma, 2004: 41 (6), 645-653

xv Williams et al, Effect of asthma on the quality of life among children and their caregivers in the Atlanta empowerment zone, Journal of Urban Health, 2000. 77 268-279 xvi Manson S et al, 2009, The cumulative burden of oral corticosteroid side effects and the economic implications of steroid use, Respiratory Medicine, 103, 975-994



The Primary Care Respiratory Society supports Asthma UK's objections to the ACD recommendation that omalizumab is not to be used for people with severe asthma.

We have seen that omalizumab has had truly dramatic results in a small group of patients with severe allergic asthma and are very concerned that these patients will not have the benefits of this treatment any longer. The negative effects of high dose steroids are considerable in patients' lives and removal of omalizumab from the armamentarium will result in omalizumab patients returning to a life dominated by the difficulties and side effects associated with high dose inhaled and oral steroids.

It appears that this product has been used responsibly and in line with NICE guidance from 2007 and in line with the licensed indications, and initiated by specialists in the relevant patients. In the absence of any significant new evidence on the effectiveness of omalizumab, it is puzzling how NICE has arrived at a different decision from its previous review of the evidence on adults. We must draw the conclusion that either the first decision in 2007 or this decision is therefore not sound.

We urge NICE to consider carefully the content of the submission from AsthmaUK, and to reconsider the proposal not to recommend omalizumab.

The Primary Care Respiratory Society has also reviewed and supported the submission by the British Thoracic Society.

November 28 2012

### Reactions to NICE announcement from people affected by asthma

### **Online reactions**

'Xolair totally changed my life. The thought of a life changing treatment not being available to anyone who needs it is appalling. It is only given as a last resort anyway, so considering reducing prescribing it is ridiculous. Not being able to breathe, being so restricted in your everyday life, and then dependant on oral steroids that will affect your health in so many ways is a difficult way to live, and my heart goes out to anyone, especially children with their lives ahead of them, who is coping with this.'

'I'm on Xolair, and it's the only thing keeping me going'.

'My daughter has been on singular and Xolair for yrs and has made a huge difference.'

'Xolair has saved my son's life. He is stage 5 and very severe - he been using singular for years. I will be very concerned if it's stopped as we've been told by doctors his asthma will kill him.'

'Xolair has changed my life. I have been on it just over 4 years, I had to stop it when I found out I was pregnant and ended up having an attack at 26 wks pregnant resulting in me being in ICU ventilated in a coma till 30wks pregnant. It's a very important medicine for those people it helps!

My son's on Xolair and its fantastic. It has given him his life back hasn't had a major attack for over a year. Took a while to get funding as he is so young but was well worth it. Worked when nothing else did.'

'My daughter was on Xolair for 2 years....such a difference it made to her quality of life. It was stopped in March and although her asthma is playing her up again they won't put her back on it due to the cost so she is back on countless inhalers and frequent asthma attacks.'

'My wife's on that it's cut down on hospital admissions and only 1 ITU admission in last twelve months.'

'My daughter has been on Xolair for around 4 years. It has made a huge difference. She has injections every 2 weeks.'

'I've been on Xolair for about 4 and a half years and it has helped me so much. My biggest fear is if it's taken away I will be in and out of ITU like I was before I started it. I have gone from 60mg of Prednisolone a day to currently 4mg.'

'I have been on Xolair for over 4 years. Before I couldn't say sentences without being short of breath. Life is very different now. Recently I completed a 17 mile bike ride! It's a saviour!'

'I have just started on a trial of Xolair. Had my first injection 4 weeks ago & my second is next week. I'm now down to a maintenance dose of 10mg of Prednisolone & I have everything crossed that at the end of the trial Xolair will be working well & I can get off the oral steroids altogether.'

'I've been on Xolair for 4 and a half years and it's changed my life completely. Before I was constantly in and out of hospital, and my quality of life was low. Now I'm working full time, feeling great and having a happy life. Such an important drug, I hope NICE reconsider their decision.'

'Can't believe it. Xolair has totally changed my life.'

'Its amazing, I started 6 years ago and it totally changed my live around, I was told there was nothing more they could do and was basically going to die, then I started this and I'm here today living a life. It's so sad for people in the position I was in as it could be their last life line.'

'My 11 year old just [read] a newspaper article about this and burst into tears. She is on week 9 of a 16 week trial for Xolair and she had been able to do PE for the first time in 2 years. She will be pleased to learn that she will be able to stay on it. She has also not had any hospital admissions since being on it which is a miracle. She still suffers some symptoms but not nearly as bad as she was'.

'My son is a severe asthmatic not well controlled and had been told he would have to wait until he was at least 12 to get it (he's 9). This is really bad news for us. It seems severe asthma is seen as very low priority, despite the fact it has such a devastating effect the quality of life of the asthmatic and their family. Most people perceive it as been a bit wheezy. They should spend a week in the life of an asthmatic and see something as basic as breathing is so hard.'

'This is shocking. I have been on Xolair since 2009 and it to has totally changed my life, I can not understand why this decision has been made surely it costs more to pay benefits for those who can't work due to allergic asthma, that to pay for the medication itself?'

'I've been on Xolair now for 31/2 yrs, I myself was at death's door every week, there was nothing they could do for me anymore. How can they say if they are stopping it now?'

'My story...Before Xolair, my life was very different to my life today, 3 1/2yrs on the treatment. I have to go to Wythenshawe every, 2weeks to have my injections, 3 in total - this drug has made my life complete today. I was having emergency admissions every week, not knowing if I would make it, or if they could save me. I will give you an example of an attack in my words:

I would start to wheeze, and feel breathless. I would take my Ventolin inhaler, after 2 puffs, and still feeling tight in my chest. I would have a nebulizer with my oxygen, if this did not ease my chest, I would then have to have a second nebulizer. The protocol was on the second then to phone for a ambulance, as I deteriorate very quickly, when they arrive who ever is with me at that time has a protocol to follow. At this point I'm getting the feeling of my chest being crushed, and the only way I can explain is someone has their hands around my throat squeezing tighter every second it's getting harder to breath, focusing on getting into the zone. Whoever is there making sure that I'm getting back to back nebs until the 1st response turns up, & making sure my letter is at hand to give them on how to respond to my attack, as I'm not a normal asthmatic and very severe. By this time I'm getting weaker by the second, in my mind I'm thinking 'oh no here we go again, am I going to make it this time?', or 'is this the last time I see my loved ones?' They strap me in the chair and take me to the ambulance, where they try to put a venflon in, which has to be done to get my medication into me. This can take a while as my veins are poor, all the time I'm getting worse. They manage to get the venflon in and start to inject me with adrenaline to keep me alive until they get me to recus, at this point I'm either unconscious or in and out of consciousness. They pre warn ICU, and there is an anaesthetist in there ready to tube me. At this point I'm so weak and can't move, but all I hear is the nurses in the back ground saying 'come on stay with us', over and over while one of the doctor is trying to take blood gases. All the time I'm thinking 'this is it my time is up, I'm never going to see my beautiful daughters and step-son again, or see my loved ones. Every second feels like a life time, then I hear 'she's back she's back'. I start to feel the ease, as I look up and see Steve smile, but at the same time he has tears in is eyes and is so frightened. After hours of fighting to breath, I've finally made it, but it's not over because there have been many a time that I've crashed after they have got me stable. Then it's days of being away from my family, this is so traumatic for one person to go through once in a life

time never mind having to go through this every week. This is my story, pre-Xolair; my body and mind also my loved ones could not go through this again if they take this drug off me.'

'They have stopped my sons use of Xolair as they say its made no difference to his asthma but we think it did make a slight difference, we are now being admitted every 2weeks to hospital again for asthma attacks my son is only 10 yrs old and getting so fed up. There's days when he doesn't want to take his medicine because he knows within a couple of days of stopping steroids his peak flow is back down to below 100.'

'My daughter is 15 and has been on Xolair since she was 12, her quality of life has improved so much and we even managed to get her off her high dose of steroids because of the benefits of this drug, would be such a shame if other people were not able to have this opportunity.'

'I've been on Xolair since I was 12, I'm now 15. I go for the injection every two weeks. Whilst been on the treatment I have been taken off Prednisolone after a severe asthma attack. I had a nebuliser and an Epi pen at home but rarely use my nebuliser.'

'I think NICE just does not realise what difference it makes talking Xolair instead of high level steroids - They may think its not cost effective - but that is looking at it very short sightedly! They are not considering the fact that Xolair patients are usually able to "contribute to society" as they are able to work, look after their families and live pretty normal lives ... Whereas life on high level steroids is everything but normal. Apart from dealing with the "soft" side effects (hair loss, weight gain, thin skin) there are also heavy long term issues - like heart disease and osteoporosis, etc to look at this is not taking in to consideration that one is feeling "poorly" most of the time and is not able do as much as one likes or wishes.'

'I am lucky to have been having Omalizumab injections for over three years and would hate to return to life pre Omalizumab.'

'I have been on Xolair for the last three years it has changed my life I have joined a gym and started swimming again something I could not do before I started it.'

'Xolair has changed my life and I cannot go back to life without it...'

'I've been a severe allergic asthmatic for the past 20yrs and for the past 4yrs I've been on omalizumab. Before then I was constantly hospitalised once or twice every couple of months with severe exacerbations. Since taking it I'm lucky just to have an admission 2 or 3 times a yr. It works.'

'My son was on xolair 2yrs ago when he was 14 but was only allowed to b on it for a certain length of time b4 being taken off as was told that his body wud need a break from it and hasn't been told if he can go back on it or not'

I know it works for some people, but Xolair certainly didn't work for me and it led to a long stay in hospital and needless to say haven't been near it since.

'Xolair has changed my life been on it 3 years. Can do things was not able to do before being on it like going to the gym, swimming not wheezy all the time. hope that people can still get the chance to try it. Hope they do not change the guidelines as my Ige was not high but high enough to get the injection.'

'I've not long started it. All I can say is my life is changing every day. I slept all night for the first time in 3 years due to having allergic asthma. It's so nice not struggling for breath and my kids are loving it. I feel like I'm getting my life back after a long 3 years of not sleeping due to coughing all night'

'I am waiting to go on it. My consultant from Wythenshawe hospital is fighting for it. I have severe allergic asthma and steroids don't work. If I can't get this, then I will have to have the bronchial thermoplasty procedure. But then again it all comes down to funding.'

'Xolair has been amazing for me! Let's hope something can be done so others can get the drug!'

'My daughter [X] is on Xolair life saver given her a new lease of life. Would be tough without it.'

'Government yet again putting money before patients. Drug for severe asthmatics Xolair is to be stopped'

#### Correspondence

'I'm an asthma patient in the U.S. that uses Xolair. I went from 70% lung capacity to 107%. Dr. Montanaro at OHSU in Oregon has prescribed it to great success.

I'm hoping that the decision to stop providing Xolair in the UK is just a ploy to get the ridiculous cost down.

When it hit the market in the U.S., I wrote Genentech. When they wrote back, they indicated that the cost was roughly \$100 a gram to produce.

Surely the NHS can talk them down, considering the incredible difference between cost and price.'

'I'm 25 years and had asthma all my life. It was always well controlled with the occasional asthma attack. I started my dream job of becoming a veterinary nurse when I was 16 years. When I was about 20 years my asthma took a turn for the worse and I was having continuous asthma attacks resulting in hospital admissions. I couldn't do anything without not being able to breathe. I got referred to a specialist had various tests. They discovered that I was highly allergic to all animals, pollen, dust mites, fungus etc! The main one as animals as my career was with animals!

I was told to quit my job on numerous occasions as it was making me very ill I then started on Xolair, this drug has completely changed my life! I have to have 4 injections every 2 weeks which isn't nice, but I would have it any day compared with asthma attacks. I can continue with my job and my love of animals. I owe my life to xolair! This drug makes such a difference to people's lives and I'm very grateful that I got to have this drug. I can't believe there stopping people have it! It costs far more for the people to be admitted every month with asthma to hospital than it would for them to have xolair. I here they are saying it will be maintained with steroids! I hate those things, although they help no one wants to be on those long term! Xolair is amazing and a life saver!'

'As a resident of the Isle of Man, I began to have my asthma properly investigated and managed upon moving to London where I was at University. I was seen by the Royal Brompton. I was due to be admitted for assessment in December 2007, but this was delayed until the January to allow for exams for my degree. That Christmas Eve, I suffered a massive asthma attack and arrested. I was thankfully resuscitated, and woke up in hospital on Christmas morning. After a then further year of prednisolone treatment, I began Xolair in January 2009 after NICE approval. I have not had an asthma attack since. The drug has revolutionized my life, from since childhood having been plagued with brittle asthma. My nebuliser is now a thing of the past!' 'As a severe asthmatic - I've relied HEAVILY on Xolair since 2007 - when it gave me my life back. Although my asthma is still classed as severe - it certainly helped me - and I doubt I would still be here without it. I worry that it will be withdrawn from me - and I will have to rely on steriods even more than I do now - which is a terrifying concept - with all the side effects. In my view - this is just a cost cutting exercise, but sadly it's hitting the most vulnerable - the chronically sick.'