Comments sent to NACC in recent days from patients currently receiving maintenance treatment with anti-TNF therapy. Their comments illustrate the difference regular treatment has made to their lives.

[redacted]

I am a 33 year old Indian male. I was first diagnosed with Crohn's disease after a resection in 2002. I was constantly suffering for a period of time after that. I was put on steroid therapy and my health improved. The disease flared again in late 2005. I was on steroid therapy and azathioprine for a long time. While the health condition temporarily improved following steroids, it gradually declined. At this time I found it very difficult to perform moderate physical jobs, exercise and to eat. My weight plummeted down to 55 kilos which is very low for a person who is 6 ft tall. Several hospital admissions followed.

At this point I developed perianal disease. The consultant put me on inflixmab as no other drug worked. After the first couple of infusions, I came to remember how it was to live normally. Infliximab brought back my work and personal life up to a great extent. I was able to eat well, sleep well and exercise.

Unfortunately, whilst the disease in the small bowel was controlled very well, the perianal fistulas and abscess got worse due to the extent of the disease. I had to have a stoma in order to rest my colon and the infliximab was stopped. Life continued fairly well, but the fistula struck again. At this point, it was recommended that I have a Proctectomy, so that the diseased parts will be removed. Another option was adalimumab. I wanted to try the drug first and have been on it for about 3 months.

I can positively say that I have never been this better(touch wood, touch a whole forest) in the past 4 years. My weight is good and climbing healthily. I can exercise and work 60 hour weeks without feeling constantly tired.

Even though it has only been 3 months, I can see a lot of difference in my physical side of things, as well as how I feel mentally. Where few months ago I couldn’t sit on the world's most comfortable sofa, I can now cycle 5 miles to work everyday without a trace of pain. Most recent blood tests show my inflammation level at all time low of the past 5 years. My iron levels are the highest since 2005. My confidence is up and my wife and I think we are now ready to have children.

We do not much know of the long-term effects of adalimumab. There is that slight 'what next ?' fear always lingering at the back of my mind. But the present has never been so good. So I hope the future can be as good too. Adalimumab has made a bit difference to my lifestyle, without which I would be facing immediate proctectomy, further pain and uncertain professional life.

[redacted]

I felt compelled to email you after reading about the potential changes regarding Humira maintenance. I have had Crohns disease in both small and large bowel for 11 years, I'm now 27 years old. During this time I have tried every possible medication other than surgery which my consultant is reluctant to do due to the complexity of my disease.

I was hospitalised in June for a flare up, resulting in extreme pain caused by stricturing. 3 courses of IV and oral steroids later and I still wasn't in remission. My consultant and colorectal nurse had to push the local PCT Trust for funding for Humira to be prescribed in my severe case and I finally received it in July.

I now have fortnightly maintenance doses of 40 mg pen injections on a ward in the local Hospital. Humira has made a huge difference to the pain levels I was experiencing. I am almost pain free. I wonder if the NICE advisors understand how it feels to be out of such chronic constant nagging pain.

Upon reading the news that NICE guidance is to stop maintenance treatment I feel very scared, upset and fearful of being taken off humira prematurely and flaring up again just now I am starting to actually live my life fully again. I understand that Humira is a somewhat expensive drug but it is invaluable in giving people like myself who have tried every other alternative without success, their health back. I urge the NICE advisors to rethink their guidance plans.

[redacted]

My partner suffers quite badly from Crohn's Disease. Infliximab has transformed her life in the 2 years she has been on it. It is potentially disastrous that the maintenance treatment she gets is likely to be removed if the NICE recommendation becomes policy at the final appraisal meeting on 22 October. The annual cost for a course of Infliximab is I think about £12K, so going privately is not really an option for us.

Her medical team are appalled at the prospect of their patients having to relapse before being allowed to administer this very effective treatment. They are trying to influence the decision. I note on the NACC website that you are taking the lead on this for your organisation.

We have already written to our MP and are submitting comments to NICE through their consultation document. Is there anything else we can do? What do you think the chances of changing their minds are? This is hugely worrying.

[redacted]

Just over 5 years ago I was diagnosed with Crohn's and it gradually got worse and worse and although I have received fantastic care at The Royal Bolton Hospital from the IBD nurses and [redacted], to quote the Verve "the drugs don't work".

I have had 3 doses of Infliximab and I cannot describe how Infliximab has changed my life. My son has a Mummy now (he has only known me ill with Crohn's), my husband has his wife back and I feel so well and happy again. Even after 1 dose of Infliximab the change in my health was a miracle.

I really hope to continue with the maintenance treatment; I do not want to wait to have a relapse to have another course of treatment. Surely if the treatment works for an individual patient. to maintain remission you need the Infliximab.

I know it is expensive and it's a cliché but what price is a patient's health and happiness?

[redacted]

I've been a Crohn's patient for the past 12 years. I was lucky enough to have an 8 year remission (achieved using elemental diet), but unfortunately in early 2006 the disease flared up again.

Steroids don't work for me, so the risks associated with losing the biologics altogether owing to antibody production if I have to come off the maintenance regime I'm currently on could be significant, if methotrexate alone isn't sufficient to prevent the antibody production. As far as I can see there's no detailed research on these risks, and the NICE decisions is, for me, the wrong one. If I lose the ability to take infliximab and adalimumab through antibody response, then as far as I can tell the next step is surgery. My concern is that for patients like me, there's no safety net (corticosteroids - I know they're pretty unpleasant but they have to be better than surgery) before surgery. We're being potentially left very high and dry by the new proposal.

Having said that, I consider myself lucky to have had access to infliximab for the past two years. I ran the Great North Run for NACC last year, am running again this year but for a different charity. Neither run would have been possible without the introduction of infliximab to bring me into remission in 2006 (regardless of whether or not I needed the maintenance infliximab treatment - we can't know this since I haven't relapsed, but it's possible that just the methotrexate without the infliximab may have maintained my remission). If I come to the conclusion I need a maintenance infliximab regime, I will find a way of going private as frankly I'd rather incur the expense than allow Crohn's to control me, rather than the other way around.

[redacted]

This treatment which I currently receive regularly has made a huge difference to my quality of life. I was getting fistulas, peri-anal abscesses which had to be treated surgically. Walking and exercise was uncomfortable and painful and I looked a bit like rhesus monkey. I was gradually able to reduce my steroid intake. I currently receive four infusions a year and really notice a worsening when my next infusion is due.

I have had CD for 14 years, with 2 major operations in that time, and very severe associated sacro-iliitis. Have been on maintenance infliximab for 12 months. I am very concerned about NICE's recommendation 1.6 against such maintenance therapy.

[redacted]

I was diagnosed with Crohn’s Disease by Addenbrookes Hospital at the age of 11 years old. I experienced an anal fistula which proved to be extremely difficult to treat resulting in 6 months off school. During this time I was transferred to West Suffolk Hospital Bury St Edmunds under a paediatric gastroenterologist.

My drug regime included Asacol, Azathioprine, Metronidazole, Steriods and Ciprofloxacin. The illness was relentless and combinations of immunosuppressant’s and diet replacements failed to prevent regular flare ups.
It was obvious that Crohn’s was having a drastic impact on my life, I was constantly unwell, tired and suffered continual diarrhoea and severe stomach pain.

A Colonoscopy, Endoscopy and Barium Follow Through confirmed severe ulceration throughout my entire gut.
My school work continued to suffer as I was unable to attend on a regular basis.
My consultant applied for and gained approval to use Infliximab when I was just 14 years old.

The effects of being given Infliximab were instantaneous, previous symptoms of stomach pains, and fatigue ceased and my inflammation levels dropped dramatically. For the first time in years I felt myself.
Infliximab was given every eight weeks for a year. This resulted in me being in good health for 2 years.

At 17 years old I was transferred back to Addenbrookes, a major flare up occurred at this time, continuous nasal gastric feeding with elemental diet, pentasa and immunosuppressant's failed to help and resulted in poor attendance at Sixth Form College. I was unable to complete my AS exams and had to complete the year again. Infliximab was given to me for the second time (November 2007) and proved to keep my Crohn's Disease under control. This helped me attend college, achieving A's and B's in my AS levels in 2008.

I am now completing my final year of 'A' levels and have a positive outlook on my life and future. Infliximab is the only treatment that works for me in preventing recurrent flare ups of Crohn's.

This drug has given me my life back and the joy of living again. I have the prospect of going to University and doing the normal things an 18 year old should expect to do.

My quality of life would be drastically affected if Infliximab treatment is used for symptomatic relapse only. This approach will result in me being hospitalised as the medication response will not be quick enough to prevent flare ups.
This will result in me needing more medication and surgery.
As you will appreciate this is not desirable at my age, and leaves limited options for surgery at a later stage in my adult life.

I have done nothing to deserve Crohn's Disease and by limiting the amount of Infliximab given (symptomatic relapse only) is unfair on those like me who rely heavily on Infliximab to make them well enough to achieve their full potential.
I cannot contemplate going back to life before Infliximab. I urge NICE not to introduce this symptomatic relapse treatment regime.

[redacted]

To give you some background I am a 38 year old lady (non-smoker), married, with one son who is 10 years old. I was diagnosed at the Christmas of 2001 following an emergency laparotomy. After which time I was prescribed Pentasa (Mesalazine) in tablet form, then to help with the absorption of the drug I changed from the tablet form to granules.

Unfortunately the Pentasa failed to keep the Crohns disease at bay, I changed to azathioprine and I also required steroid treatment (budesonide), regrettably this did not work and I required my 2nd bowel resection in January 2006. I had a tough time with this surgery, a couple of days after I needed to receive an emergency blood transfusion. This was a very worrying time for my family. Although the surgery was successful, I continued on the azathioprine but the disease was active again late in 2006 and I required my 3rd bowel resection in April 2007.

At the end of 2007/beginning of 2008 my condition was giving cause for concern and I had an colonoscopy carried out where thankfully this time they found no narrowing of the bowel as yet, but detected some crohns ulcers again, therefore previous treatments were not working so I started the infliximab treatment, unfortunately I experienced a number of side effects to this drug (severe joint and muscle pain in knees and legs, rash and itch skin) and was transferred on to adalimumab, to date I have had no problems with this drug.

Also to add complications to my condition, I am a patient who unfortunately the normal CRP “inflammation” triggers are not conclusive as mine in general the maintain the same level, therefore the only true diagnosis is through a colonoscopy examination.

Removal of my access to regular adalimumab treatment would cause me:

- Almost certainly daily discomfort, I am finally able to lead a life free from abdominal distension, at severe times causing me to vomit. If you have ever experienced this you will know how painful this can be.

- I would also be at risk to an increased amount of Crohns ulcers at the site of my small bowel, which would lead to further narrowing of the bowel, thus the need for further bowel resection surgery. Surely the costs associated with this surgery and the subsequent weeks of hospital care would out way the costs of the use of adalimumab?

- Having access to probably the best colorectal surgeon in the UK (Professor Neil Mortensen), having already had 3 bowel resections (Dec 2001, Jan 2006 & April 2007), any type of surgery poses risks, a risk I do not wish to take lightly. Certainly for me further surgeries would also run the risk of a colostomy bag – I cannot even contemplate my life with this.

- Increased pressure, stress and worry on my very supportive husband and family. My family and I deserve a quality of life, my son has since the age of 3 had to cope with me being ill - it is very hard when you are being admitted to hospital and he cries going to bed that he does not want you to die, I cannot put him through this anymore.

- Although I have a very supportive employer (BMW (UK) Manufacturing Ltd), this tolerance will not continue. I have already exhausted the majority of my company sick pay, therefore further absence will cause me and my family financial hardship, which in the current financial climate would put my mortgage repayments at risk.

  Prior to receiving the adalimumab treatment I was off work for:

  170 days (34 weeks) in 2006
  267 days (28 weeks) in 2007

  In this current climate what company could possible sustain an employee being absent for work for this amount of time?

Since starting the adalimumab treatment on 6th March 2008 I have only been absent from work for 10 days this was as a result of kidney stones. When I was admitted as an emergency on 24th August 2008, the initial diagnosis was a stricture or perforation to the bowel, thankfully due to the success of my adalimumab treatment it was only kidney stones.

- During 2006 and 2007 had to put my career on hold, I was a HR Manager but due to my condition at the time I felt I was not able to fulfil that role. I am now starting to rebuild my career again and have just accepted a HR Specialist position. Removing me from the adalimumab treatment would have a detrimental affect on my health and thus my ability to carry out my new role.

I would ask that you please think long and hard about the decision you are about to make. I appreciate the position you are in but please do not remove something, that since my diagnosis in 2001 is really working for me just because it costs too much money, that is just not fair. My husband and I have both been full NHS and taxpayers for 22 years. I also believe that removing adalimumab access for Crohns patients will be a step backwards in the relief of the symptoms of this chronic illness.

[redacted]

Prior to maintenance infliximab I

- relapsed frequently
- had 2 bouts of major surgery (needed TPN in 1st) – 1 month as an inpatient in 1st, 2 weeks in 2nd
- had at most 2-3 months at a time off medication
- there were many obstructive episodes with vomiting - inpatient care for some of these with HC intrevenously, pethedine/morphine
- other CD related hospital visits
- countless days off work, especially > 2 months around 2nd operation
- pain and fatigue at other times
- many GP appointments, phone calls, blood tests

I took/was given:

- 1000s of painkillers
- steroids almost constantly usually <40mg/day,
- dietary supplements (Fe/Ca/Ensures etc)
- many courses of antibiotics (inc. 8 in one year) for abcesses and diaorrhea
- immunosuppressants over 9 of these years
- 2 periods on elemental diet

I had 2/3 infusions of Infliximab in mid 2007, which were effective for 3 months, then relapsed rather badly. With particularly bad associated sacro-iliitis.

Since starting Infliximab every 2 months.:

- no surgery
- no hospital visits (other than clinic appts & these infusions)
- no sacro-iliitis
- no steroids
- no NSAIDs/codeine painkillers, but some paracetomol for

migraines/colds
- stopped immunosuppressants 6 months in, none since
- 1 course antibiotics
- my CRP has been below 10 for the first time since diagnosis

(had reached 110 twice in 2005-6)

I am acutely aware how close I was (before maintenance infliximab) to being unable to hold down a job, and needing sickness/unemployment benefit – instead I work as an IT consultant and pay tax.

What about hospital/GP time not just for CD but for the many associated conditions, common with severe CD? My experience suggests that this cost to the NHS on top of the medical/surgical costs must be great.

Rather than suggesting it be available to all patients, does the analysis look at whether maintenance Inlfiximab would be cost effective for just the more serious cases of CD? And does it do so accurately, taking into account all the factors above? These factors must be common to many patients with severe CD.

The NICE appraisal consultation document seems to say we are waiting for better evidence in this debate. If so, I think there is a danger of making a decision that could be disastrous for me and those whose CD is similar or worse than mine. If the argument runs: "we don't really know if this is cost effective so lets not fund it till we do know" then I would urge them to listen to cases such as mine and allow consultants to employ maintenance IFX for selected, serious cases of CD.

As far as quality of life is concerned, before maintenance IFX

- there were many very painful, very unpleasant episodes of obstruction with vomiting.
- extreme fatigue, leading to depression. Anxiety due to uncertainty.
I never felt far from the next flare-up
- last October, my sacroiliac disease became so bad once I took 40 minutes to get to the next room to eat so I could take the painkillers (which I knew were harmful but felt I couldn't live without) The pain from this was unquestionably worse than that of the 2 major surgeries I have had for CD. The episodes of this debilitating level of pain were frequent pre regular INFLX.
- I barely held onto a job, and did so partly because my employers understood my condition. Obviously, not all severe CD sufferers will be this fortunate.

In the last year none of these has been a problem, my quality of life has been improved wonderfully. I have said to friends and family (before hearing about the NICE recommendations) that Infliximab has changed my life, now it could be changed back again, for me and presumably for others who will have to endure the cycle of relapse-treatment-relapse, and waiting to see if they qualify for episodic infliximab.

I hope NICE can be persuaded to reconsider this, and that maintenance IFX can remain available to patients with more severe CD,

PS: I can't find it now but I think there was some evidence somewhere suggesting that episodic IFX treatment was more likely to lead to the waning of usefulness or antibodies, as opposed to maintenance?

[redacted]

I know it is rather late in the day, but just thought I would share my thoughts and comments on infliximab or adalimumab. I had 3 infusions of infliximab in March, and I am now on my 4th month of having humira. I have had crohns disease for approx 14 years. I have had all the medication possible to treat my crohns, which has meant I have been on steroids since I was diagnosed. Ranging from 5mg to 40mg when required, along with azathioprine. I have been told that "I have reached the end of the road medication wise" and humira is my last hope. At the age of 15 I had an ilestomy bag and fortunately this was reversed, the only option now is to have this procedure without any hope of a reversal. The humira is keeping my crohns under control, and although it has not healed my fistula ,I have a good quality of life. The thought that the funding could be stopped is most distressing, as this drug is helping me, and although I know at some point it may stop working, but it would be good that this could happen of its own accord, rather than a decision of funding, to seal my fate.

[redacted]

I was originally diagnosed with ulcerative colitis in 1987. Between 1987 and 2004 I only had occasional flare ups and generally kept quite well.

I was made redundant in July 2004 which coincided with becoming extremely unwell. I became too unwell to work and was unable to seek further employment. In Oct 2004 I became so unwell with severe abdominal pain that I was admitted to hospital for 2 weeks for treatment of an abdominal abscess. After further investigations I was diagnosed with Crohn’s Disease, and although I recovered from the abscess the Crohn’s symptoms persisted. I am very stoic by nature and my symptoms have to be extremely bad before I complain.

I spent most of 2005 feeling generally unwell, unable to consider a job and barely able to maintain life as a housewife. In January 2006 I went on a liquid diet, lost a lot of weight, but felt better. Returning to solid food by way of an elimination diet was unsuccessful and I had to return to the liquid diet. Although a liquid diet alleviated the symptoms of Crohn’s disease I was no longer able to join my family for meals, dinner with friends became a thing of the past and my quality of life in general deteriorated.

In June 2007 I had another 10 days in hospital, but my symptoms were not stabilized.

Finally in July 2007 I started infliximab. It transformed my life and I was able to function normally again and enjoy life. I felt so well I was able to return to work in April 2008 and resume playing tennis. I have had infliximab infusions at a maintenance interval of 8 weeks. This period was extended to 10 weeks but resulted in the return of symptoms.

However, since being on infliximab the strategy of introducing Azathrioprine and Mercaptopurine has been unsuccessful.

I am frightened for my future if infliximab is stopped. My husband and I have 3 children, one of whom has Cystic Fibrosis, for whom I am the designated carer. I have parents in their mid to late-80’s and my mother has severe Alzheimer’s disease. They are struggling to live independently but refuse help from outside organizations. Being their only daughter and living locally much of the responsibility falls on my shoulders. The health of both my daughter with Cystic Fibrosis and my parents would deteriorate if I was unable to give them care and attention due to deterioration of my own health.

The extra income I provide from employment is extremely useful in helping towards the financial burden of my children attending University. If I became unwell and unable to work this income would cease.

Comment from a NACC member:

I have read the consultation document for infliximab and adalimumab with great interest, however, I am concerned that the document states that the drugs will not be available as maintenance dose therapies on the grounds of cost. Severe colitis and crohn's are both physically debilitating and psychologically debilitating illnesses, often leading to long term unemployment and other types of exclusion and isolation. I believe the quality of patients' lives should not be measured against cost and I believe this on ethical grounds alone.

In addition, it seems to me that such cost cutting is ultimately a false economy, if patients can be kept free of active disease with maintenance dose treatments, less impact will be placed on NHS funding for the longer term, with less hospital admittance and far less likelihood that surgery will be needed at a future date, resulting in overburdening professional care that arises in both these situations.

In a wider sense, maintenance dosing will lead to less disruption in peoples employment lives, it is now very well documented that when people are unable to work their physical and mental well-being suffer, thus potentially making further demands on health services. Lastly, as for children, avoiding active disease with maintenance dosing has to be paramount, rather than bouncing them between active disease and remission. Active disease is likely to take them away from their schooling both formal education and the social skills they learn from being with peers and generally part of the school system, a serious loss to any child, which could be a disadvantage they carry though into their adult life.

Comments from people on paediatric use of antiTNF therapy

[redacted]

I am surprised about this NICE decision as we as a family have found this very useful with [redacted] He has really settled well with this treatment. His general and physical wellbeing has improved rapidly since starting infliximab. We hope the Authority at NICE will reconsider their decision concerning this usage of Infliximab in Paediatrics age group.

[redacted]

hi it is [redacted] i am writing you this letter because i am worried about being taken off imixfliab as this is my exam year and i cannot afford any time off school, as i had to much time off in the past few years which has effected a lot of my grades and notes i need for revision.

from when i started the imixfliab i have been in school everyday and been really well, where as with modulin and pantasa kept me well for a short period of time then i got put on a long course of steriods which kept me well while i was on them and when i stopped taken them a few weeks later i was ill again so i got put on back on the modulin then the doctors took me off that and put me on azathioprine which kept me well for longer but i had to have a few courses of steriods while i was on this. so being put on the imixfliab i done me a lot of good i have been really well and doing everything a teenager should, e.g going out with friends, shopping with my sisters, staying up late, staying at friends houses and visiting family abroad where as when i was on the other medications i could not do any of that as i was too weak.

[redacted]

Hi my name is [redacted] and I am [redacted] big sister. I have been informed that you are considering take [redacted] off of her Infliximab. I am writing to try and persuade you to reconsider your decision as since she has been on this medication she has seemed a lot healthier. But every time she is taken off of her medications she ends up back in hospital again. Before she was on this Infliximab she was extremely ill, at the point where some days she had absolutely no energy to do anything at all, always tired, always needing to go to the toilet every few minutes, and always feeling extremely low through and through. I was one of the few people that spent a lot of time looking after Katrina while she was ill and in hospital and having her in my arms crying from not being able to do the normal things that all teenage girls do.

Before she went on this Infliximab she hated not being able to come out shopping and having our days out like we always did before she became ill but as soon as she went on this medication she able to get up and come out and has the energy to act like a normal teenage girl again. She is enjoying being able to go out without having to worry if there is going to be a toilet there and being able to go into a public bathroom without having to worry about what the next people that go in will say. She is no longer the odd one out at school.

Please do not take her off of this medication, she is so much happier and back to the old [redacted] again. I am worried that if you do end up taking her off of her medication she is going to end up having to miss loads of school again and back in hospital. She has only just recently been able to relax again. Please keep her on this medication.

[redacted]

In reply to the Crohn’s disease –Infliximab (review) and Adalimumab: appraisal consultation document.

My son was diagnosed at age 12 with Crohns disease. He is now 16 years old. It would be accurate to describe his disease using your own definition (paragraph 1.2)

The following is a brief outline of his treatment history since diagnosis:
1. Nutritional treatment – Modulin
2. Immunosuppressant -Azathioprine
3. Steroid - Budesonide
4. Antibiotics - Metronidazole and Ciprofloxacin
5. Surgery - Bowel resection
6. Infliximab

Between each course and type of treatment after the initial remission period his Crohns either remained active or became active after some time. His growth was behind that of his peer group and his puberty was delayed. It is only since treatment began with Infliximab that he has been in steady remission. This in turn has allowed him to grow and go through puberty (albeit about 3 later than his peer group).

To the best of my knowledge Crohns disease manifests itself in the same manner for both paediatric patients and adult patients but with one major difference. The bodies of paediatric patients are developing, and they are going through a process of emotional maturation as well. Crohns disease has a huge impact on the growth of paediatric patients. It can lead to growth retardation as Crohns interferes with nutritional absorption. In patients beyond the age of 10 it also often results in delayed puberty, as is apparent in my son.

I list the 5 types of treatment above that my son had prior to Infliximab. With all these treatments there was an impact on the quality of his daily life. There was the general feeling of being unwell, pain coupled with adverse reactions to some medication, and most important the resulting disruption to his education. Added to this was the emotional pressure of seeing ones peer group growing and going through puberty whilst he lagged behind. He had to cope with not knowing the outcome of each treatment and the subsequent emotional turmoil that came with the acknowledgement the disease was active again.

When looking at the evidence you have collated I question the validity of the QALY measurement used in the analyses. I do not dispute that this is valid for adult patients but I do not believe the same QALY measurement cannot be taken for paediatric patients. As Crohns disease often affects growth process and puberty, as described above, this puts paediatric patients in a totally different category to adult patients.

I challenge the recommendation in paragraph 1.6 as I believe effective medical care should be categorized by finding the optimum manner to cure or control a disease. If a drug such as Infliximab accomplishes this, there surely is a duty of care by the medical establishment to achieve the following: ‘successful treatment focuses on inducing <u>and maintaining</u> clinical remission’ (paragraph 2.6). Infliximab can ‘induce remission’ and used as maintenance therapy can ‘maintain clinical remission’.

In regards to Crohns disease I do not believe it is <u>‘plausible to generalise studies in adults to the paediatric population’ (paragraph 4.3.13)</u> In general the disease manifests itself in the same manner for both adults and children but the issue of growth retardation is a differential which does not affect the adult population.

In conclusion I sincerely hope that the committee takes into consideration the further needs of the paediatric patients that they can <u>‘potentially benefit more from treatment’ (paragraph 4.3.13)</u> and that the **quality – adjusted life years measurement** is given more emphasis with regard to children who have had to grow up with a chronic illness. Maintenance therapy has enabled my child to grow, be educated and hopefully reach his potential in adulthood.

[redacted]

[redacted] has asked me to write a paragraph to explain, from the school’s point of view, how being in remission has helped [redacted]chool life.

I knew [redacted] when she was in the Junior School. Prior to her current treatment she was very, very poorly. She required a considerable amount of time off school, and could sometimes only manage part of a day. Despite having a very supportive family and hating being away from school, she just did not have the energy and was never free from pain for long enough to fully take part in school life. [redacted] constantly struggled to keep up with work and her friendships started to suffer as she was not able to join in games at playtime and was absent for periods of time.

Since starting the Infliximab [redacted] is a different girl. Her attendance has much improved and she is a popular girl with a gathering of friends. She is a keen sportswoman with a lot more energy. As the School Nurse, I rarely see her other than when she escorts another girl to the medical room for treatment. [redacted] is now able to be in control of decisions affecting her life and seems to live life to the full! A positive sign of her improvement must be her decision to travel to Beijing for a 7 day school trip later this year – a daunting journey for most of us.

[redacted] (and her family) certainly has an improved quality of life and it would be tragic to see her deprived of this should the Infliximab be withheld from her.

Please do not hesitate to contact me if I can be of further assistance.

NACC
October 2008