

Patient voice

Patient experiences of biologic treatment for severe asthma: the good, the outstanding and the deeply frustrating

In this article, Jenny and Niamh, who both have severe asthma, share their very different experiences of biologic treatments. Both have found biologics to be effective but Jenny, who over time saw a reduced benefit, has been unable to access further biologic treatment and pleads with researchers to develop, with patient input, further treatment for people on oral corticosteroids. Niamh talks about the gradual and severe escalation of her asthma, her immediate transformation using biologics and her return to physical activity.

Jenny Negus

Jenny is 45 years old with difficult-to-control, severe asthma. She was previously on biologics, but over time found the effects diminished and was taken off Xolair (omalizumab). The following is Jenny's experience of navigating the healthcare system to manage her asthma.

I had my first asthma attack at the age of 18, but my asthma didn't become a major issue until my late 20s. I have multiple hospital admissions each year, three so far in 2021, which can include visits to the high-dependency unit. My asthma has various triggers including allergies, viral infections, weather conditions and stress. I have several related health conditions that also impact significantly on my day-to-day life. These include osteopenia (thinning bones), cataracts and severe fatigue.

I was started on Xolair approximately 8 years ago. At the time my blood IgE levels did not meet the

criteria for prescribing it, but my doctors decided, given my other symptoms et cetera, they would initiate the 16-week trial. The benefits were immediately obvious, especially a reduction in the impact of environmental allergies. I got sunburnt for the first time in years, which I suppose isn't really a benefit, because I was finally able to spend time outdoors.

After 7 years on Xolair, and in the wake of an increase in exacerbations and a higher medication load, it was decided to stop the Xolair as it no longer seemed to be of significant benefit. It was explained to me that the improvement in my environmental allergies was not having a big enough impact on my asthma management to warrant continued treatment with Xolair. Allergies are just one piece of my asthma puzzle. Since stopping it in November 2019 there has been no change in exacerbation levels, but a definite increase in seasonal allergies. No more sunburn for me!

I was initially told that being on Xolair would affect my blood tests, and a "cooling off" period of 4–6 months was needed before trying a different/new biologic.

Alternative biologics have been discussed as possible treatment options; however, I have hit a barrier that I am unable to breach, namely the National Institute for Health and Care Excellence (NICE) prescribing criteria guidelines for biologics. To qualify I need to have a certain number of exacerbations in a given period; not a problem I meet this criterion. I also need to have a certain number of "treatment" courses of oral corticosteroids (OCS)

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Biologic treatments can be life changing, apart from when they are not; healthcare professionals and researchers must not forget those for whom biologics are not an option. <https://bit.ly/3DJVmxP>



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Jenny Negus.

in a given period. I meet this too. Where I come unstuck is the blood test criteria. For all the biologics currently approved by NICE for use within the UK National Health Service (NHS), patients have to show certain eosinophil levels within their blood.

I have a reading of 0.0–0.2 and to qualify for biologics the level must be ≥ 0.3 . When I asked about this, I was told that OCS suppress eosinophil levels, and that stopping my OCS for 3–5 days should allow me to get a higher reading. However due to 15+ years on varying doses of OCS, namely prednisolone, I am steroid dependent. I therefore have to take daily maintenance hydrocortisone to stay alive. Also, my lungs seem to require 6 mg prednisolone on top of the hydrocortisone to give me any asthma stability. I have been told by my endocrinologist and respiratory consultants that stopping all OCS for 3–5 days is not a safe/viable option. This therefore effectively, in the UK, writes off my access to biologics.

This would not be the case in many other European countries because, while measuring eosinophil levels, they also acknowledge the impact of OCS on them. Blood eosinophil levels are not a pre-requisite for prescribing a biologic as they are within the UK NICE guidelines.

At a logical and practical level, I understand that NICE need to set guidelines and protect the finite resources of the NHS, and that exemptions cannot be made. I am also aware that NICE guidelines committees include patient representatives, which I am all in favour of, and am considering applying for this role myself in the future. Patients from all ends of the disease spectrum need to be represented in the regulatory decision-making process. However, from an emotional personal standpoint I am angry that I have to miss out on an emerging range of treatments which might improve my asthma control and could positively impact on my quality of life.

My current asthma management has now taken an alternative course, away from biologics. The focus is now on improved stability to allow me to make the most of my life, whilst also minimising my dose of OCS. In practice this means that rather than pushing myself to “get better”, and then

crashing down when I push too hard, I am now trying to accept the limitations my health puts on my activities and take life at a steadier pace. This has involved accepting the presence of more physical symptoms on a daily basis, and a major psychological shift in mindset. The main benefit to this course of action is a wholesale reduction in my consumption of prednisolone, the side-effects of which were blighting my life. I am still, however, dealing with some long-term comorbidities such as sleep apnoea and skin/tissue weakness.

Biologics have been developed on the back of a push to reduce the use of OCS, the long-term detrimental effects of which are universally recognised. My plea to researchers and the medical profession is not to forget those people with asthma, who for various reasons, are not suitable for biologics. Please keep developing new areas of treatment that can reduce the use of OCS, and please involve patients in the process, as asthma is our “thing”!

Niamh Cullen

Niamh is 46 years old and a primary school principal with three children, she was diagnosed with asthma when she was 27 years old following a chest infection she could not shake, and her resulting inability to exercise. The following is Niamh’s account of her journey with biologics. Niamh was interviewed for this article and the following is a summation of our discussion, which she has read and approved.

It started off bad, but not too bad. My sister has had asthma since she was very young, she’s been on Xolair for a long time, nearly 15 years, and I knew that my asthma wasn’t as bad as hers. As time went on though, my asthma got progressively worse and was always very severe when I was pregnant, I was hospitalised during each of my pregnancies. Each time it was harder to recover and by my third and final pregnancy with my son who is now 11, I was signed off work. I couldn’t walk upstairs without coughing and having to sit down. I remember my other children saying to me: “Mummy, why do you always cough when you laugh?” It had really taken over my life, progressively, and slowly, I didn’t realise



Niamh Cullen.

the impact it had had, but I was in a pretty bad place at that stage. I was waiting for him to be born, hoping it would all be fine after the pregnancy.

But very soon after my son's birth, in July, I had another chest infection and was back on oral steroids, I was consistently ill from then until February the next year. I went for an X-ray in January and assumed all would be fine. They put a mask on me and put me in isolation as they thought I had TB, due to the X-ray. I was kept in hospital for a week while they did tests and found it wasn't TB but a very bad exacerbation of my asthma. They also discovered that my eosinophil count was very high.

I was given steroids and sent home, I was told I'd be sent a referral which arrived in August, by which time I was ill again.

My referral sent me to a different Professor who scanned my airways and found that I had very bad sinuses; he referred me to an ear, nose and throat (ENT) surgeon and I had a number of operations that took away some polyps and made it easier to breathe.

The theory was always that my asthma was made worse when my sinuses were bad. The team I was working with were incredible. No stone was left unturned; we tried a non-sulphite diet, every combination of antihistamines, maintenance antibiotics and maintenance steroids, but nothing was really working.

I took part in INCA SUN [1], a study led by the Royal College of Surgeons that looked at adherence of inhalers to ensure that I was using my treatment in the most effective way. From this trial they found that my F_{ENO} was very high, in the 80s. We managed to get this down with all the different treatments for a while, but my baseline was just too high. I was in a spiral of exacerbations, taking 6–8 doses of oral steroids each year. Although I was thankfully never

hospitalised after that, as the team worked so hard to keep me stable.

The Professor said that there was a treatment coming that could help but they didn't have it yet; so, we waited. In March 2019, I was very ill, my F_{ENO} was up around 155 and I was sent to the respiratory nurse for another cocktail of drugs. They then told me that I was a candidate for biologics.

My aspirations were to come off oral steroids all together, but my respiratory team told me to be reasonable, they said that I might be able to wean myself off them but there was every chance that it wouldn't have such a big impact. We agreed that if I could reduce them and manage to sleep I would be overjoyed.

I started biologics in August of 2019. I really cannot emphasise this enough: overnight, I was a different person, it was just incredible. I was able to reduce my other treatments dramatically, I was still on maintenance steroids for a little while and finished these in April 2020 after being on them for 18 months. I weaned off them slowly, 2.5 mg at a time, and I did not experience any negative side-effects from the wean. Since then I have not needed oral steroids. I still use my preventer inhalers, but I should be able to reduce the dose of these too, the pandemic may have slowed this down as I have not had face-to-face meetings.

Before biologics, I was using my blue inhaler, salbutamol, perhaps 4–5 times per day; since, I have used it just four times in total, once very early on and the other times were triggered by exercise and some scented candles.

I no longer feel as anxious about having asthma, which can be a huge draw on life, carrying that burden around with you. I have been able to get back to exercise which I really missed, I can sleep and I am feeling very well – I almost forget what life was like before the biologics.

Affiliations

Jessica Denning, Jenny Negus, Niamh Cullen

European Lung Foundation, Sheffield, UK.

Conflict of interest

J. Denning is an employee of the European Lung Foundation.

References

1. Moore A, Preece A, Sharma R, *et al.* A randomised controlled trial of the effect of a connected inhaler system on medication adherence in uncontrolled asthmatic patients. *Eur Respir J* 2021; 57: 2003103.