

Appendix 1

National Rheumatoid Arthritis Society

Submission to NICE in respect of 2nd Appraisal consultation document:

Adalimumab, etanercept, infliximab, rituximab and abatacept for the treatment of rheumatoid arthritis after the failure of a TNF inhibitor (part review of NICE technology appraisal guidance 36, review of NICE technology appraisal guidance 126 and 141)

This is [REDACTED] story, so far ...

My name is [REDACTED]; I am 24 years old and was diagnosed with rheumatoid arthritis in the year 2000. I used to be a confident art student at a top art school in London with great expectations of becoming a successful artist. I was looking forward to my life and all the possibilities and opportunities that lay ahead. Then on one day my life changed, I had an allergic reaction to Infliximab (Remicade). At this point I wasn't really concerned as the NHS had up to this point been so great at keeping my illness under control, I was sure I would be put onto another drug that would put me back on the road to recovery. Unfortunately I was wrong; I was flabbergasted when I found out that I didn't make the trials for Rituximab and couldn't understand the reason why I wasn't accepted as there were no other good medication options for me. For the next year my RA got progressively worse and all the NHS could do was give me the drug Humira (Adalimumab) which had already been proven to be ineffective. My specialist had fought hard for me to get on the trial for Rituximab, so when I was rejected I felt a great deal of anger and frustration towards the NHS and NICE. I couldn't believe that there was a drug available that could possibly help me but instead I was watching my life, as I knew it, slipping away and no one was trying to help me stop it.

For one year my specialist was trying desperately to keep my RA under control, using various medications that just weren't working effectively. For that year the disease rampaged through my body destroying my joints. My specialist tried again to get me on trials for Rituximab this time at Guys hospital; in the mean time I was praying that the PCT would fund the treatment. During that year my health deteriorated drastically. I lost all my mobility, I couldn't walk or get out of bed because of pain and discomfort of my swollen joints, and I couldn't even make it to the toilet. I needed full time carers (through social services); adaptations (stair lift, bath lift and other basic adaptations) throughout the house as I couldn't even do the simplest of tasks anymore. I didn't recognise myself I felt like I was cocooned in the shell of my body feeling helpless and alone. As my problems got worse it was putting a strain on my home and social life. Before I had carers my parents who both work full time had to help me with the most basic of tasks (getting dressed, assistance getting to bathroom) making me feel like a burden to my own family. My social life hit a stand still as I was unable to go out and meet friends as I was too unwell to really leave the house. A bone density scan also revealed that I would now be prone to Osteoporosis as well. The highly aggressive RA took its toll on my body leaving me with other related illnesses like Sjogren's Syndrome (body stops producing saliva and other body lubricants

leaving you with dry eyes and dry mouth). This had a devastating effect on my already exhausted, rundown, frail body. I was unable to eat and lost so much weight. I was 35kgs at my worst, consequently putting me at higher risk of developing bed sores. I was put under the care of the District Nurse and Dietician in my area. I also suffered terrible anaemia, leaving me tired, lightheaded and nauseous, which added to the risks of falls and the lack of desire to eat added more problems to the weight issue.

Whilst I was living through all of this, I felt like a prisoner stuck in a body that wouldn't work, my life was restricted to my bedroom. What kind of life is this to live?: trapped in my room, unable to eat, walk, use the toilet, even breathing and sleeping was agonizing and the pain if the duvet rested on my body felt like it was crushing me like a heavy weight on every joint. As for the damage that was being done, it was so rapid and aggressive, it left me feeling helpless and hopeless because I felt so alone and worried that when they finally gave me Rituximab (MabThera) would I be too broken to be fixed? In the space of that year the erosion to my shoulder joint was so severe I lost the use of my right arm completely, resulting in a total shoulder replacement in 2008. My Left hip was also left with irreparable damage, resulting in a total hip replacement in 2009. My life wasn't worth living; no words can describe the pain, the discomfort and the frustration I felt through this time.

The saddest thing of all is that the damage is irreversible. I will never be able to live a normal life or hold down a job because of the irreversible damage done to my wrists, hands, fingers, ankles and feet. My whole life has had to change significantly because of one year waiting for a drug to be okayed, but my plea to NICE is please don't do this to the patients who need to go onto Abatacept and Tocilizumab (RoActemra). Give us options, because without them we are stripped of everything, our health, our independence, our dignity, our pride and our hope for a brighter future. The longer RA sufferers go without treatment the less chance we have of getting any kind of quality of life back. I look at the money spent on OT equipment and adaptations, physiotherapy, dieticians, district nurses, full time carers, hip & shoulder total replacements (between £4,000 - £7,000 per operation, and because of my age, I will be needing them replaced again in the future due to wear and tear), and the burden I will now be on the government for the rest of my life because I will never be able to work full time is immense. This could have been prevented if I was put on the drug a year before saving the NHS much needed money. By giving patients with RA effective treatment at the right time, we can live near enough normal lives, we can work and it slows down the damage done to joints resulting in less need for joint replacement operations and numerous other hospital facilities that are only needed when treatment is not provided and RA is not effectively controlled. We need reassurance that our lives won't be ripped away from us if the medications that are available stop working. If things don't work out with Rituximab (MabThera) for me, it is a terrifying thought to think I will have to go through all this and more because I won't have the options of Abatacept and Tocilizumab (RoActemra). **Help us control RA by giving us options.**



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