

Rea Mattocks – Why it is vital to approve the commissioning of anti-TNFs for severe, refractory uveitis – My Story



As a qualified social worker, I was finally working in my dream job as Director of Social Services when suddenly, one day in August of 2005, my world turned dark. It was as though all the lights had been turned off and I didn't know why.

The next day, I fell down the steps into my office as I had lost my depth perception, and then my ability to see different colours diminished markedly. I knew something was badly wrong and I went to see my optician, who immediately sent me to the local ophthalmology accident and emergency department. Initially, I was told it was my 'age' (I was 51 at the time) and it was 'normal' to have these vision problems.

Within two weeks, my vision was so poor that I could not see the cars in the road and was nearly run over. I returned to accident and emergency, where I was seen by a consultant who told me I had inflammation in my eyes and immediately prescribed steroids. He decided to further investigate the cause of the inflammation and so started a long journey into ill health and life with loss of my vision.

After three months of various tests, I was diagnosed with Birdshot Chorioretinopathy, a rare, potentially blinding, auto-immune, severe, refractory form of posterior uveitis, which is believed to affect 0.14 people in 100,000. Birdshot destroys your retinal and choroid layers, which leads to blindness. The first line of treatment is immunosuppressants and steroids which help to tackle and address the symptoms but not the disease. In addition, because the eyes are immune privileged (they are able to tolerate the introduction of antigens without causing an inflammatory immune response), treatment requires high doses of medication, and has implications for long term health.

These high doses had a traumatic effect on my personal and work life. I became prone to hyperactive, aggressive and manic behavior. I raged at my staff, I alienated my friends and family, I laughed inappropriately, I slept for two hours a night and I thought I could fly, and tried to launch myself off a seventh floor balcony. I was also constantly ill and had to have a sick bucket by my desk at all times.

Every time I tried to reduce the medication, my eyes flared up again, leaving me blind. My consultant decided that as the disease was not adequately controlled on low enough doses to protect me against long term illness, we should apply for an anti TNF, adalimumab (Humira) which works by blocking the activity of bioactive mediators of the immune response. This means that you can reduce or stop use of steroids, thus saving your health.

Whilst my employers waited patiently for me to become stable, and supported me endlessly, my health continued to deteriorate as the effects of the medication has left me with osteopenia, memory problems and some mental health problems.

The application for adalimumab was turned down, despite the fact that it was being used for uveitis in many countries around the world at the time, and even in England for a lucky few.

So within three years of discovering I had Birdshot and as my health, behaviour and vision had deteriorated markedly, I reluctantly retired in 2008. Had I been given the adalimumab I could have carried on working for at least another ten years and instead I felt I had become a burden to society and a huge cost to the public purse. I no longer contributed taxes and was in need of constant medical attention for my many illnesses, infections, deteriorating vision and deteriorating bones.

On appeal 18 months later, I was finally able to access adalimumab for two years, which was too late to save my career or my health, but miraculously stopped the inflammation, and gave me back some sight. It allowed me to function and carry on as a productive individual. Had I been given adalimumab at the critical time, I could have saved my vision, saved my sanity and saved a huge cost to the public sector.

If you have been diagnosed with Birdshot Chorioretinopathy, and would like advice and help, please access the BUS (Birdshot Uveitis Society) website at: <http://birdshot.org.uk/>

Birdshot Uveitis Society was set up by two people with Birdshot, Rea Mattocks and Annie Folkard to provide information, to support people, to ensure early diagnosis and thus, stop needless loss of vision and to encourage research into the disease.

About Rea Mattocks

Rea Mattocks has been a member of the Lay Advisory Group of The Royal College of Ophthalmology since 2012. Her personal experiences of the NHS in general and ophthalmology services in particular provide a genuine perspective and a clear understanding of patients' experiences from the good and bad to the terrifying on their journey to retaining or losing their vision.

Rea believes that good outcomes for patients are more than just about the treatments and medications they receive. Good outcomes are very much dependent on a patient's total experience and the relationships built up between patients and the 'clinical and health care team'.

Rea comments, 'Patients, too, have a responsibility to make the best use of the NHS and the 'contract' between patient and clinical staff is vital to the health and well-being of the NHS in general as well as individual patients and clinical staff.'

Rea's other role as Patient and Public Engagement representative on the Clinical Commissioning Group for Ophthalmology Specialised Commissioning, provides a full and unique perspective of all sides involved in the ophthalmic care and safety of patients.

As a member of the Lay Advisory Group, Rea feels it is a vital opportunity where her experiences can be used in a positive way and where her continued learning about the clinical and medical aspects, including the clinician's viewpoint, is invaluable to support the work of the Lay Advisory Group.

About RCOphth's Lay Advisory Group

The RCOphth's Lay Advisory Group is made up of members who have no background in health or eye matters, members who are or have been eye patients and members who have a link to eye or health related organisations. The group includes clinician members of RCOphth including the President. While the Lay Advisory Group is not a patient lobby group it expresses views based on public and patient experience of health and eye care services.

The Lay Advisory Group is an integral and influential group within RCOphth and supports decisions on policy and guidance to ensure that the patient's voice is always heard to improve and maintain patient safety and care.