

**Board Meeting in Public
Tuesday, 28 March 2023**

Corneal Donation and Transplantation - A Patient Perspective: Laura's Story

Laura was 20 years old when she went to an optician for what she considered would be a routine eye test. She had been experiencing some slight blurring of her vision in her left eye when she woke in the morning, but it corrected itself quickly and she never considered it a serious problem. The eye test discovered what was termed a 'scratch' on her right eye and she was referred to Moorfields Eye Hospital.

Moorfields investigated Laura's symptoms but struggled to determine an absolute diagnosis as her symptomology was atypical and various medications to ameliorate her symptoms seemed to make no impact. The hospital felt a diagnosis of Herpes simplex virus (HSV) infection was most likely, even though the symptoms were not typical. HSV is extremely common, though usually latent, up to 90% of UK population is seropositive for HSV with primary infection usually in childhood, then the virus lies dormant in trigeminal ganglion. The condition usually affects one eye but may be bilateral, especially in severely atopic patients. Symptoms very variable: Pain, burning, irritation, photophobia, reduced visual acuity and redness.

Laura's symptoms worsened over a period of several years. The clouded vision she had experienced upon waking and early morning gradually extended until she was dealing with blurred vision in the eye all day. She explained her symptoms as being similar to wearing filthy dirty glasses all day, struggling to see the world through the dirt, it is an analogy that gives a clear insight into the struggles her condition imposed upon her. Her condition impacted on every area of her life, from the seemingly trivial through to the huge, as examples Laura outlined that she would use a pen but then be unable to place the top back on it, the act made impossible as she could not align the top and bottom. On the other end of the spectrum she would be trying to navigate her way through Euston Station in rush hour and would bump into commuter after commuter, unable to see the people coming towards her and take evasive action.

Eventually Laura's condition worsened to a point where her medical team informed her that the only treatment available to her was a cornea transplant. Laura admits she was nervous at the prospect but aware of the fact that she had no other options. The cornea transplant was carried out under general anaesthetic, a fact Laura was relieved about as she was nervous at the thought of the procedure. Following the transplant Laura was placed on a regime of steroid eye drops to aid healing and prevent rejection. These were started at very high volume, literally applied every few minutes, and then gradually reducing back to use daily. Laura is stoical about the regime, and the need for ongoing follow up with the Moorfields Team, considering it a price more than worth paying for the gift of a cornea and improved sight.



Laura and her family today

Following her transplant Laura reflected on the truly remarkable gift she had been given by her donor and the family who had supported their gift. Many years before, at a time when she was asymptomatic, Laura had been faced as so many citizens are, with the opportunity to register her organ and tissue donation wishes. She had recorded her wish to donate all her organs, with the exception of her eyes. Her choice at that time made Laura realise the challenges faced when donation professionals seek to obtain consent for cornea donation. Having benefited from a cornea donation she determined to try and help, she commented on an Instagram post about organ and tissue donation, and someone responded and asked her to share her story. Her response was to film a video telling her story and explaining the remarkable gift of cornea donation from the very personal perspective of her own story:

video <https://youtu.be/7JQXYBJVI2o>

10 years after her first cornea transplant Laura was experiencing symptoms in her right eye and was informed she would need a second transplant. Now married and expecting a child, this transplant had to wait until Laura had her baby and had finished breastfeeding. For this surgery Laura felt more comfortable with the process and was prepared to have the surgery under a local anaesthetic. This transplant has now been in place for 8 years and, while Laura now experiences some blurring, she is incredibly grateful for the time she has benefited from this gift.

In the years since her last cornea transplant Laura's family has continued to benefit from the unique gift of eye donation. Laura's mother went into hospital for routine cataract surgery and, as is always a small risk in this procedure, suffered cornea damage. Her sight has also been restored by cornea donation, meaning that a remarkable 2 generations in one family are living with the benefits of eye donation.

Laura explains her relationship with eye donation as follows. Her life has not been 'saved' in the traditional sense we mean when we talk about the beneficiaries of organ donation. However, her life has been changed by the cornea transplants she has received, had they not been available thanks to the benevolence of the donors and their families Laura is in no doubt that all aspects of her life, family, work and social, would be different. Laura thinks of her donors and their families every day, she states that she cannot articulate how grateful she is to them for their donation, her work to spread awareness and understanding of the need for cornea donation is a tribute to them.

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