

NHSBT Board Meeting

A Patient Perspective: Allogeneic Serum Eyedrops

29th March 2022

Status: Official

Louise Buchanan is a 56-year-old recently retired Civil Servant and proud mother of one who resides in the Isle of Wight. Louise suffers from Sjogren's syndrome, an auto immune disease she contracted after 2 episodes of Glandular Fever, one at 15 and one at 20, caused her own immune system to start attacking itself. Usually presenting as a rheumatological disorder, the glands in the eyes which are affected by Sjögren's are the lacrimal (tear producing), and the meibomian (oil producing). Louise suffers symptoms which are on the severe end of the spectrum, in particular extreme dry eyes. Louise has been using eye drops since her early 20's but through the last 15 years noticed that her eyes were becoming much more difficult to manage. The Sjogren's destroys the mucus membrane and the macreous glands in the eyes: these are the glands responsible for the secretion of water and oils that moisten the eyes when you blink. The consequence of this is that Louise secretes a tear film that last around 3-4 seconds in comparison to a non-sufferer whose secretions will last from 20-30 seconds per blink.

It is almost impossible to describe to a non-sufferer how painful and debilitating the condition is. Louise uses the term 'Relentless' to describe the impact of the untreated condition. Even a light wind dries out the eyes immediately. In daily life Louise has to stop and use eye drops every 6-8 minutes, anytime and anyplace, eye drops live in her pocket or purse 24/7 and she could not conceive leaving the house without having them with her. Even blinking can hurt, and the pain caused can be immense, Louise has faced having to literally peel the eyelid off the eyeball when she wakes. Louise suffers every day from Chronic Fatigue and is a great supporter of naps as a recognised hobby!

Louise managed her condition for several years with over the counter drops but found over time they were less and less effective. Most of her work as a civil servant was screen based, and this exacerbated the condition as the reduced blinking rate when using technology made her eyes even more dry. Louise knew she had to look for a better treatment if she was to retain her quality of life and protect her sight.



Louise and Her Son

Eventually she was referred to a dry eye specialist nurse who gave her stronger drops which helped for another 2-3 years, these then became less effective, and the Nurse referred her to the Consultant Ophthalmologist at Southampton Hospital who prescribed cyclosporine eye drops. Louise remained upon those eye drops until a chance conversation with a fellow patient who told her about their new treatment: Serum Eye Drops. Upon hearing about Serum Eye Drops Louise raised the issue with her consultant. Following several meetings to consider her suitability for the programme, a process that felt to Louise to take quite some time, Louise was approved. Following approval Louise was asked to attend Southampton Blood Centre to give blood, so efficient was the process that Louise literally watched the blood leave the centre before she did! 8 weeks of processing later and her drops were couriered to her home on the Isle of Wight. Louise donated her blood for autologous drops 3 times, but she then became anaemic, and after those 3 donations had to stop as she felt too unwell. She then transferred to allogenic eye drops which have worked just as well. Louise has now been using allogenic drops for over 3 years and uses the allogenic drops alternatively with lubricating eye drops to maximise their effectiveness and her personal comfort.

Sjogren's syndrome is non-curable. Therefore, the focus of Louise's treatment is upon maximising quality of life. Pre-serum eye drops Louise had suffered agonising infective keratitis; her suffering was such that it made Louise question if she could continue to live in such pain. The relief the serum eye drops have bought Louise has literally been life changing. This in no way means that Louise has not thought deeply about her experiences and has questions around the treatment.

Louise was told that you must keep the drops chilled, however this does not reflect the practicalities of life as Louise noted 'You cannot carry a fridge with you'. Now Louise keeps her drops in her pocket all day, despite not being chilled she has never had an infection. Louise wanted to go on holiday but

could find no official advice on how to transport her drops. She Googled how to freeze drops and found ice packs in France which she purchased. She has since flown to Spain 3 times and is slightly frustrated that healthcare professionals had not seemed to have considered users taking holidays. Life with Sjogren's is challenging. Serum Eye Drops help Louise to live her best possible life, despite the pain and the many challenges that her condition causes every day. All thanks to the generosity of donors she will never meet and TES professionals delivering the quality service she needs.

Author

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