

## EEC, My Bladder and Me

Hi everyone, I am Julia Errington. I am 62 years old, and I have ectrodactyly ectodermal dysplasia with clefting. Over the years I have had many operations starting at two months old up to the present.

We are all familiar with the dental problems associated with EEC and I was fortunate to have titanium implants put into my jaw over 30 years ago. They have never caused any problems and they keep a well-fitting upper and lower denture in place. I have yearly appointments at Newcastle Dental Hospital to check everything stays as good as it is.



My eyes have been severely affected from being a child. Again, so many of you will be dealing with the painful effects that EEC can cause. I have had treatment and support throughout my life that has made a tremendous difference. I travelled on many occasions to Liverpool from the North East to see Professor Colin Willoughby and had treatment there. That is now being continued closer to home and I am waiting for a procedure that involves attaching a small piece of amniotic sac to the affected skin under the eyelid. This has been done on several occasions and provides a lot of relief from major irritation for several months. Isn't it amazing what can help; the nutrients from the amniotic sac 'feed' the affected part of the eye?

It is not a cure, but it has certainly helped me.

Moving on..... I contacted Diana Perry over 20 years ago when I first had the results of my genetic tests. I have followed the success and never-ending work of the Society since then but have not felt the need to contact Diana until recently.

I have always had at the back of my mind the feeling that my bladder could be affected by EEC. My mother always thought that my frequent visits to the toilet were excessive but when she queried it, was told not to worry and that I would grow out of it. I did not, and it gradually got worse. In 2020, in the middle of the pandemic and the first lockdown, I started having symptoms that were not normal. I was in the shielding category and terrified to go to the GP. Unfortunately, 3 urine samples failed to pick up signs of blood. Eventually, on New Year's Eve, a GP offered to come and see me.

I was referred as an emergency to urology and seen within days and diagnosed with bladder cancer. I was not shocked or frightened. Again, I kept thinking could there be a link between the cancer and my EEC? I told the urology team what I thought, and they were amazing. They said I was the expert and that they had no knowledge of EEC but would do their best to find out. They asked me to take any information I could find to my next appointment.

After trawling the internet for hours and finding a couple of references to bladder/kidney problems and EEC, I thought I would contact Diana. She replied quickly and sent me a link to an article that I had read and confirmed what I had thought. Diana offered to contact the Society's medical advisory board and ask if they had any further information. I received a reply which suggested I could have a background bladder epithelium that could be dysplastic and could possibly alter the treatment approach. I copied the information and took it for the senior consultant. He read through it and said it was helpful and he would take it into account during the surgery.

## Supporting a normal lifestyle

I had 7 tumours removed and my bladder was exactly as the reply had suggested, very thin. As a result, the team had a meeting and asked if I would be happy for them not to do any further operations or treatment at this time. Instead, I would have a follow up in June to look at my bladder again and take it from there.

They were pleased with the biopsy findings because the cancer is not invasive, but it did need careful monitoring and they were very happy with the information I had been able to provide.

I cannot thank Diana enough for her response to my request for help. That vital piece of information from a member of the medical advisory board alerted the urology team to things that may be different inside the bladder when they operated. It has certainly altered the course of my treatment completely and there are other treatments to be considered when they are needed.

I am very positive about my future. I have a wonderful partner, we have two ponies that are our lives, we ride and walk for miles and I have no intentions of changing anything. This is another chapter in my journey living with EEC.

I cannot stress enough that my situation will be an extremely rare occurrence, but if you or your children have any signs or symptoms of any bladder problems, please do not hesitate to get it checked.

A huge thanks to the ED Society and the personal way in which Diana has helped me and kept in touch. Words cannot express what the support has meant to me.

**Julia**

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