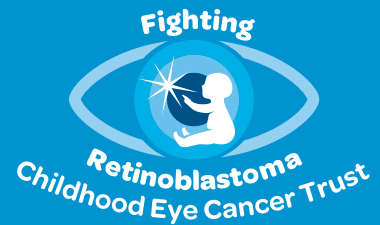


INTRAVITREAL CHEMOTHERAPY



We understand that you may be shocked or upset to hear that your child has cancer and that they need chemotherapy, especially as treatment can start very quickly. However the whole family will be supported throughout the entire process by your treatment team and your Childhood Eye Cancer Trust (CHECT) support worker.

This leaflet is not about intravitreal chemotherapy (IVC) itself, but about how families have coped with it.

Your retinoblastoma (Rb) team will explain all you need to know about the treatment and any side effects.

CHECT has always asked members to share their stories.

We know that it can be helpful and often uplifting to read other people's Rb stories. You will find the full versions of the below extract, as well as other stories, at:

www.chect.org.uk.

Imogen was diagnosed with bilateral Rb when she was ten weeks old, after her parents noticed her right eye was turning white, and her left eye had a squint.

"When Imogen was first diagnosed she went straight into six rounds of systemic whole body chemotherapy alongside laser treatment and cryotherapy.

She then had radioactive plaque treatment in a bid to reduce the size of the main tumour in her right eye, before the decision was made to try IVC.

Her consultants talked us through all the available treatment options for Imogen and which they thought would be the most effective. Because she has bilateral retinoblastoma, we needed to work on a plan to treat both her eyes. Once the tumours in her left eye were under control, we began to use different treatment options to directly target the trickier tumours in her right eye. We were extremely lucky that Imogen found IVC relatively straightforward compared to some of her previous treatments. She

had three rounds done, each whilst under general anaesthetic, and apart from some slight discomfort when she first came round, she didn't seem to find them painful at all.

Each round of IVC was two weeks apart. She would go down to theatre as normal for her EUA (Examination Under Anaesthetic) and laser / cryotherapy

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treatment, and have the injections done at the same time. This meant it took slightly longer than her usual EUA but the staff were always great at keeping us updated as to how it was all going.

Thankfully Imogen's side effects were minimal! She would often be in some discomfort when she came round, but this was easily managed with pain relief. She would have a large, clear eye shield on after each IVC which she was never very fond of, however we would remove it the next morning in time to give her the first set of eye drops.

I think that the thought of IVC is often worse than the actual treatment! Our biggest tip would be to

make sure you have all the information you need beforehand (we often found that the timeframe between deciding on IVC and actually starting treatment was very short, so ask loads of questions while you can!). And ask staff to keep you updated when they are in theatre as it can feel like they are in there forever.

We are very lucky to say that Imogen is doing amazingly well now! The IVC, alongside her previous treatments, helped to get her tumours under control, settle her retina, and allow her to reach a place where she doesn't currently need treatment! She is such a happy, cheeky little soul and we are incredibly thankful that she has had such amazing treatment and care."

Hugo was almost two and a half years old when he was diagnosed with unilateral Rb.

Having discussed the various treatment options with the Rb team, we decided to start with intra-arterial chemotherapy (IAC). However he still had vitreous seeds in his eye that needed mopping up, so we were advised to try IVC.

Hugo coped really well with both IAC and IVC. We were very lucky that he had no complications and each procedure went really well. During IAC we were lucky enough to both be able to be there and I would stay during the treatment, but when he was having IVC it was during COVID so only one parent was allowed to go. My youngest Harry was under six months and obviously I couldn't leave him with my mum, so that was hard, but my husband would FaceTime throughout the

appointment which made it a bit easier. How do you ever prepare yourself for something like this? I think the first time I saw Hugo after his first IVC I was probably a bit taken aback as he looked all swollen from steroids and had a large plastic lense over his eye with a clear film keeping it in place. Removing this was always a bit tough, but we learnt to do it in the bath where if we let him get it wet then would fall off more easily.

Hugo is absolutely fine now. He later had an enucleation, not down to the chemo not working, as actually it had done its job and he was free of treatment for almost

two years. But he developed a cataract due to all the trauma to his eye. Throughout this whole process it's never stopped Hugo being Hugo. He's a very energetic, happy, healthy six-year-old boy who now has a special eye that is a part of him.

*If you have any worries about the treatment, or notice any side effects, make sure you discuss these with your Rb clinical team.

To hear more from families whose children have gone through IVC you can join our closed Facebook group for parents, or ask your support worker to connect you with another family.

www.chect.org.uk

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