



Intravitreal chemotherapy (IAC)

We understand it is shocking news to hear 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 notice her right eye was turning white, and her left eye had a squint.

When she was first diagnosed she went straight into six rounds of systemic 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

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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 and laser / cryotherapy 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 (injections directly into the affected eye) 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.

an infection and was going through IAC chemo he was always his usual smiley happy self.



Husayn was diagnosed with bilateral Rb when he was nine months old. Having had six rounds of systemic chemotherapy, as well as some laser treatment, it was decided to try IVC.

When children have IVC they are given drops after treatment to settle the eyes and

prevent fluid and eye pressure building up. However, this didn't work for Husayn: during IVC his eye pressure went up and he had fluid in his eye after first treatment, so this had to be treated before Husayn could have the second round of IVC.

He had three different lots of eye drops, to be given four

times a day, five minutes apart. He didn't like them at all, as one stung (we were able to change this to a different one when we told the consultant). I used to make sure I did the one that stung last. He got to know that it was the drops in the orange bottle that stung (he would say 'mam, I don't want the orange one'), so I had to disguise it by putting the orange drops into a blue bottle! We have found you may have to try different drops / medicines, as every child so different. Whenever I had a concern, the consultant was able to offer an alternative. My advice

would be to make sure you speak up to tell the consultant as then they can offer an alternative.

In addition to the drop, Husayn also had an oral medication, which sadly caused weight loss, and loss of bladder control at times. He was three and a half at the time, and had been dry for a year previously. The consultant said it was the medication that had caused the weight loss and the loss of bladder control, so he halved the medication which massively reduced these side effects.

I would always have snacks ready for Husayn when he woke up, having starved the night before. He would never eat in the hospital. I would tell him he had to eat one crisp so that the nurses could let us go. But then once he was in the car he would say 'Where are my sandwiches?'

To see Husayn now, you would think he has never been to the hospital or had any treatment. As soon as he comes home and sees his brother he's back playing, making a mess of the house. He'll never remember it himself, we'll have to tell him about it.

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



To hear more from families whose children have gone through IAC 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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