

INTRA-ARTERIAL CHEMOTHERAPY



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 intra-arterial chemotherapy (IAC) 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.

Brody was diagnosed with Rb at six months old. His mum Stacey shares here her experience of IAC.

Following a referral by our doctor, Brody was diagnosed with unilateral retinoblastoma. After doctors ran some more tests, it was revealed that the cancer was contained within the eye and that not only could they save Brody's life, they might be able to save his eye too.

Suddenly a weight was lifted – we felt that we were able to cope.

After diagnosis we had a week to decide what to do –

whether to proceed straight to enucleation, or whether to try intra-arterial chemotherapy (IAC), where the chemotherapy is fed directly into the eye. It was a difficult decision to make, but we decided to try to save his eye.

Brody had to undergo three sessions of IAC, with four weeks in between each. Luckily he wasn't as poorly as some children having systemic chemotherapy can be.

However, he did have an infection (which is rare, but was treatable with antibiotics), and he was also neutropenic (low

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white blood cells so more vulnerable to infection) after sessions one and two. After just one treatment Brody's tumour shrank to half its size. There was some seeding (small amounts of tumour spread within the eye), but this was also treated by the IAC.

Brody has received his last treatment and now has to have check-ups under general anaesthetic every four to six weeks to monitor the tumour.

When your child has a diagnosis of retinoblastoma, information comes at you very fast, and making a decision can be very difficult. I would say to other parents not to panic: there are many successful treatments available. Not everything you see and

read about as possible risks or side effects is going to happen. Brody was fairly poorly at times, but this is not a common side effect.

We're not yet entirely sure what the final effect has been on Brody's sight, but it has already

improved: he can now pick up things that he couldn't before.

Brody has been wonderful throughout this whole ordeal. Even when he had an infection and was going through IAC chemo he was always his usual smiley happy self.

We asked our members about their experiences and what they found useful. Below are some of the things they shared with us.

- TV can be helpful when you're trying to convince a little one to stay lying down for four hours. Bubbles helped too.
- Don't be worried if the procedure takes a long time. I think the longest for our son was four hours. Most of it was because they can take more time to place the catheter, and recovery.
- Be prepared for an extra night's stay in case the medical staff need to

keep your child under observation a bit longer.

- Our child had a droopy eyelid, but it did improve.
- We found it useful to have distractions, such as rattles and shakers, to hand when giving the eye drops at home after the IAC.
- Although it's unusual with IAC, our son did become neutropenic once, and we twice ended up in our shared care hospital to check temperatures.
- However it wasn't as wor-

rying as with systemic chemo as there was no risk of line infection.

- We found that the medication caused our child to be hyperactive, so it was important for us to time when we gave it so that it didn't interfere with bedtime.
- You will need something to keep you comfortable and distracted while they are in theatre. Sometimes it can take longer than you might expect and your mind wanders all over the place. I find now that podcasts help so much at times like this.

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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