

PPG NOTES ON TALK ON RETINOBLASTOMA ON 26 FEBRUARY 2019

Pippa Branch, a patient at Billericay Medical Practice, gave us a talk on 26 February 2019 about children's eye cancer – retinoblastoma – and her experiences with her daughter Amber. About 15 attended including doctors from the Practice.

Retinoblastoma (RB) can be seen as 'white eye', and it is treated by chemotherapy, radiotherapy and laser treatment, which can limit sight. 50% of children suffering this have their eye removed. It can be unilateral or bilateral – one eye or two. Amber was treated at the Royal London Hospital, which made visiting hospital easier. There are only two hospitals in the country that see children with Retinoblastoma.

Approaching one year old Amber had a slight squint. At Christmas 2017 they noticed a red glow in a photo, and in January 2018 they could see the glow. They saw the GP in February 2018 and were referred to Orsett Hospital and were seen in March, when she had a sight test. She could not see out of one eye, and they could see a lesion. They returned to the hospital next day when retinoblastoma was diagnosed, and they were referred to London, with an appointment next day. Amber could not eat so she would be ready for anaesthetics, and they were told she may have to have her eye removed. Therapy dogs helped Amber in hospital. She had a general anaesthetic, and then the diagnosis of RB 'low' D.

She had chemotherapy, six doses, one every three weeks at Great Ormond Street, and her first visit was to the Oncology Department. Treatment was done through a port which they called her 'button' under her arm, with a tube under the skin to the neck and her heart. She had blood tests, antibiotics, chemotherapy anti-sickness drugs, all through this attachment. There was a risk of sepsis, and a risk if she had a temperature.

There were three different medicines on IV, 2 bags, and a seven hour process in the cot. Sitting beside her as time went on you could see the change during the process - sickness, anti-sickness cocktail changes, and sick on the way home. There was hair loss which did not bother her; there were food changes each cycle – what to feed her. Eating was very important, it did not matter what it was. There was energy loss and by treatment six she had no energy. There was a cycle of food/blood/sleep and she did not want to be on her own. Neutropenic – she was isolated from her friends/family/activities and could not be exposed to bugs. There was a chicken pox scare.

During treatment she had 5 platelet transfusions and 3 blood transfusions. She was very prone to bruising and had a lack of colour and energy. Blood donation is very important for cases like Amber.

There was a brilliant support network of Community Nurses who came once or twice a week depending on blood counts. They answered questions and helped with medication, prescriptions, flushing, saline, heparin, sharps bin. Pharmacy got things sorted, and the Doctors made it work. The community

play therapist distracted Amber when having blood tests. Amber did not like some of the treatment and she was encouraged to play with equipment to help her feel less worried.

They went to Basildon Hospital as necessary for transfusions etc, and stayed in the chemo room for overnight stays in hospital. It was possible for a parent to stay for 24 hours. She was not allowed to play with other children in the play room, and was on her own. In hospital there was sleep disruption. Genetics: it was initially thought that it would be unlikely for Amber to have genetic RB – a blood test has been done. She has genetic RB. The parents were tested. Amber has a 50% chance of passing it on.

At the time of the talk Amber wears an eye patch regularly 99 minutes a day which stimulates brain to eye connections. She can now see 4 metres away. She will have regular eye checks under GA until she is four. There is an 89% chance of a relapse. It could develop in the other eye. There will be booster injections as Amber has lost her immunity. The parents always explain everything to her.

At the hospital there was a bell rung when special occasions happened like end of treatment. She was given beads of courage.

Raising Awareness: signs for early diagnosis to save a child's eyes.

Charities which have supported her:

Children's Eye Cancer Trust www.chect.org.uk

Spread a smile – entertainment in hospitals

Sick children's trust – Stevenson House where parents can stay near hospitals during treatment

Pyjama fairies – special pretty pyjamas which are much better than a gown

For more information about retinoblastoma, what to look for, and where to get help, contact the Childhood Eye Cancer Trust (CHECT) via www.chect.org.uk