

# Retinoblastoma: the parental perspective

Katy Bishop<sup>1</sup>

**Katy shares her and her son Owen's experience of battling with Retinoblastoma and the birth of the Owen Bishop Charity Fund.**

**M**illions of people across the globe have been affected by the devastating consequences of cancer. Many patients, families and care givers have been distraught, shattered - and yet many have eventually come away from their experiences even stronger. Katy Bishop, is one such remarkable lady, who as mother who saw her son, Owen, from exhibiting symptoms of retinoblastoma, and journeyed with him through diagnosis and treatment. Katy and her family's struggle has led to an immensely successful initiative, "The Owen Bishop Charity Fund", which runs various campaigns, to raise both funds and awareness of retinoblastoma. In an extremely moving account, Katy reflects upon her experiences and provides an invaluable perspective as a parent.

## The first signs of trouble

As a mother of four children, I was pretty content and thought my life was pretty perfect. However, in 2010 my life changed as I knew it, as I was hit with the news of my son, Owen, having a form of eye cancer, which is commonly known as retinoblastoma.

Owen was 10 months old when he was initially diagnosed with retinoblastoma. He was referred for an initial examination for a squint and because my three older children were unaffected, nobody was particularly worried or concerned that this could be sinister. At the clinic I was asked if I had noticed anything unusual about his vision and despite my complete lack of knowledge regarding retinoblastoma, I informed the health practitioner that we had in fact noticed his pupil to be rather unusual in some of our photographs. I was assured that this was just a camera trick and Owen was then referred to a local optometrist for a prescription. I, of course, thought no more of it. Owen attended the appointment with the optometrist and his pupils were dilated for examination and a pair glasses were prescribed. He was then seen several times for adjustments and over the course of the next few weeks his vision did not seem to improve - in fact his right eye began to shake furiously and constantly from side to side. This, I was told, was Owen trying to focus.

At his next routine hospital appointment the shaking eye was noted and I was informed that it was nothing to worry about but Owen would have to be seen by the Consultant. We waited 10 weeks for this

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### Conflict of Interest & Funding:

Katy is the mother of Owen Bishop and founder of the charity.

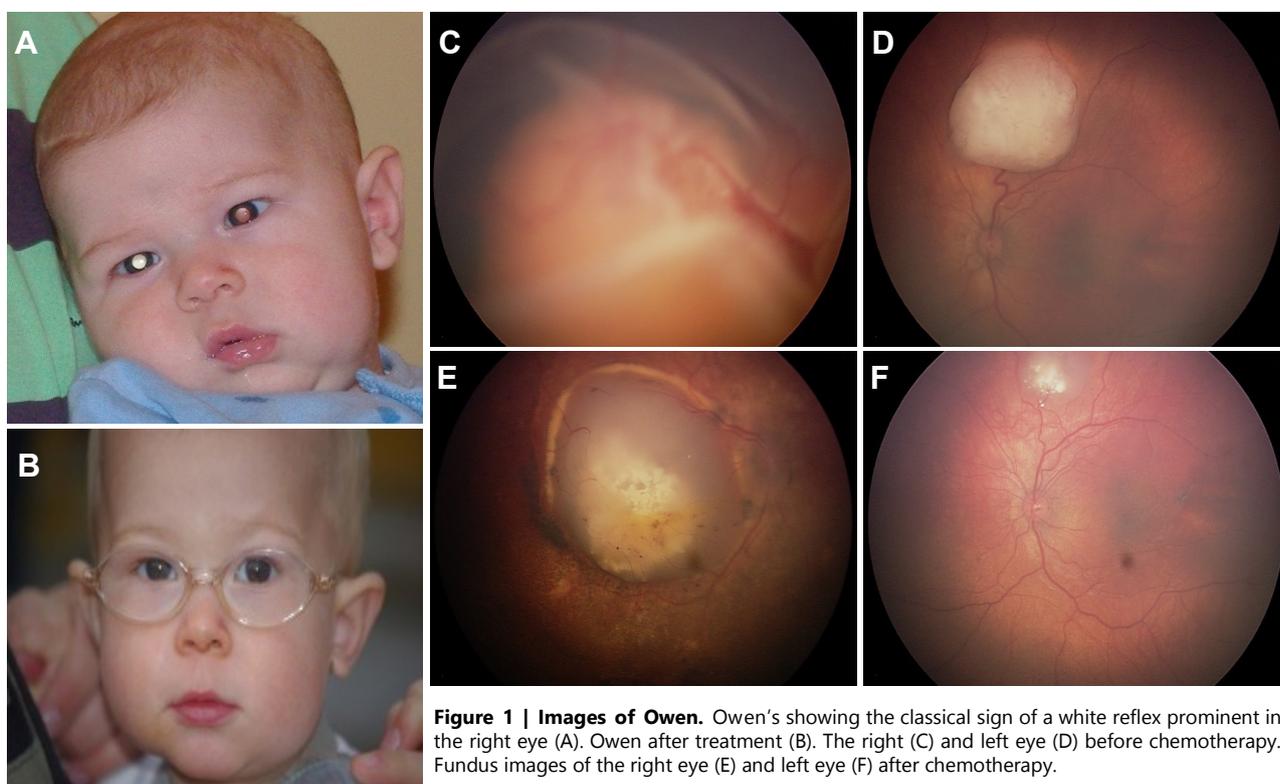
appointment and within a few minutes, the Consultant realised that there was a problem and referred Owen for an ultrasound. At this point nobody had informed me of their suspected diagnosis and a few days after the scan, I was given the news about Owen having retinoblastoma.

The tumours in his right eye were so large that his retina had detached and this was causing his eye to shake. Owen was categorised as a patient borderline for enucleation (surgical removal of the eye), however, the doctors opted for chemotherapy in a bid to save his eye. We were told that the future was uncertain and only time would tell.

### The challenges we faced as a family

The next few weeks were crazy. Our world flipped up and suddenly we became experts in oncology and were using words like neutrophils and caring for central lines. Hospital visits, sickness and blood transfusions became part of our daily routine.

Owen thankfully responded amazingly well to the chemotherapy and after a time, we were told that the tumours in his right eye had shrunk enough to save the eye from enucleation and eventually his retina reattached (Figure 1). The vision in that eye was damaged forever but at least he kept the eye. If there had been any danger of cancer spreading outside the eye; it would have been removed. Owen was lucky that despite having being given a diagnosis so late, (5 months) he had a relatively good outcome.



**Figure 1 | Images of Owen.** Owen's showing the classical sign of a white reflex prominent in the right eye (A). Owen after treatment (B). The right (C) and left eye (D) before chemotherapy. Fundus images of the right eye (E) and left eye (F) after chemotherapy.

I was, as you can imagine, devastated, but my sadness quickly turned to anger. Why had I not known about retinoblastoma? Why did the doctors miss it? How could they have missed it? I told the health professionals that I had noticed a reflection on his pupil in photographs and that he had a squint. Two classic red flag symptoms of retinoblastoma and they had missed it. Even when he presented with the wobbling eye (which I now know to be nystagmus), they failed to make the diagnosis for Owen. Consequently Owen waited some 10 weeks for a chance to see a consultant and be put on a care pathway.

I do not want to be misunderstood, Owen's care since the diagnosis has been absolutely first class and I am extremely grateful to everyone who has been involved in his care. However, the truth is; Owen was lucky. Lucky! Owen had cancer and there was a considerable delay in his diagnosis and yet he was lucky.

The specialists told us if Owen had been seen just a week or two later at the most, he would have lost his eye and we may have faced the possibility of losing him as his tumours were that advanced. I know now that around 70% of the children diagnosed with unilateral retinoblastoma undergo enucleation.<sup>1</sup> This statistic saddens me greatly. It is one I pledge to change.

### **A poor outlook**

Developing countries have such poor access to education and medical services that the survival rate is much lower – around 30%.<sup>2</sup> How sad that is. But it serves only to reinforce the magnificent medical system we have here in the UK in that around 98% of our children survive retinoblastoma. Yet 70% lose an eye? Surely this is something we can change?

If early diagnosis reduces the damage caused by tumours, thereby saving vision and potentially avoiding enucleation -then education on identifying key signs of retinoblastoma surely is the best way forward.

I googled retinoblastoma, spoke to the doctors and

armed myself with as much information as I could. I set up a Facebook page and reached out to the world. I wanted to know everything and I wanted everyone else to know it too. Awareness saves vision and lives and the day Owen was diagnosed, something was born in me. It was my mission to change the statistics. This could not keep happening and I was determined to make a difference.

### **The initial approach**

Initially I went to the hospital and made a complaint about Owen's diagnosis pathway. I was told that they had a policy that stated any child with a clear white reflex would be seen within 2 weeks. I urged them to change their policy so ALL children with ANY abnormal appearance on their pupils be referred and seen swiftly. Thankfully they agreed and as a direct result of Owen's experience they changed their policy to ensure no one else "slips through the net".

The next phase of my plan was addressing the complete absence of public awareness information on retinoblastoma. I could not believe I had never heard of retinoblastoma and the more families I spoke to, the more apparent it became that many others had also been unaware of retinoblastoma until their child was diagnosed.

Retinoblastoma can be ridiculously easy to spot, IF you know what to look for. The white reflex, the glow, the cat's eye (Figure 1). This is the most common way to spot it. You do not need a medical qualification to see that white glow. Parents take hundreds of photos of their children. If only they all knew what that white glow could mean.

### **Taking things to a bigger platform**

So I began writing to the Department of Health. I had identified the Birth to Five book and the Personal Child Health Record or "little red book" as it is often referred to, as the key resources for parents to access health information. These books are held by EVERY parent in the UK and would be perfect platforms for this information. I wrote a proposal for change and outlined what changes I felt needed to be made to

their books and the information I felt needed including.

Responses were lukewarm at first but I continued to write and as my campaign grew, I approached my local MP for support and drafted a letter for other parents to contact their MPs. The Childhood Eye Cancer Trust (CHECT) offered its full support for the campaign and indeed it became the focus of the trust's Retinoblastoma Awareness Week campaign in 2011, which saw unprecedented global media coverage. They used my proposal for change as the basis for a petition, which I then promoted using social media and enlisting thousands of supporters online, which even included celebrity interest.

### **Achieving the first milestone**

CHECT worked behind the scenes, liaising with the professional bodies that governed these books. Together we pushed from inside and out and 2012 saw the fruits of our labour rewarded with 100% campaign success!

The Institute of Child Health wholly accepted our proposal for changes to the PCHR and agreed to initiate the changes with immediate effect. Soon after I was told the NHS Choices website had also revised its website to include information on the signs and symptoms of retinoblastoma, in the serious illness section of the child and baby area alongside meningitis and other high profile illnesses. We have been told NHS Choices is taking over from Birth to Five now so I could not have asked for a better outcome. The other advantage about getting this vital information into these places is that medical professionals will become increasingly aware of retinoblastoma too.

Health visitors currently receive no formal eye care training. CHECT is now working hard to make sure health professionals understand the reasons behind these changes. Now that this information is included in these respected resources, it not only offers information for the medical professional but also empowers parents to insist on their concerns being listened to.

There is clearly an urgent need for the medical professionals to be better educated about retinoblastoma and it not be dismissed as a rare cancer not worth learning about.

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***"We are encouraged to brush our teeth twice a day. Eat our five a day. Exercise appropriately. Why doesn't anybody ever say, "Go and have an eye test"?"***

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Now I have seen my campaign through to fruition I devote my time to raising awareness of the condition and fundraising. I am supporting the trust's new campaign and hope one day to become a trustee of the charity. I spend time daily building social media support for them and raising awareness of retinoblastoma.

This is how the Owen Bishop Charity Fund came about. There have been so many people and organisations involved in Owen's care and, as a fundraiser, I wanted to be able to support them all. So I set up the fund as a way of raising money in Owen's name, in honour of his fight against cancer, but it allows me to divert the funds to any charity I want. The funds always go to children's cancer charities with my main recipient being CHECT.

Since starting this charity fund two years ago, we, as a family and with the support of our community have raised nearly £10,000, nearly all of which has gone to CHECT. We've walked, played golf, collected money tins, hosted an "It's a knockout!" competition, given numerous interviews for newspapers and magazines, been on BBC and ITV news and I even got nominated for an inspirational woman of the year award! It has been crazy and fun and extremely challenging but worth every minute. Yet it is still a drop in the ocean compared to what Owen has and continues to endure.

Many people contacted me via the Owen Bishop Charity Fund and social media who have concerns

about friends or family members' children saying if it wasn't for my posts they would never have known about retinoblastoma. Moreover, CHECT is aware of several children who have been diagnosed as a direct result of a parent having seen an article in the media or on TV so awareness raising is absolutely essential in the fight to save vision and lives.

### **Aims for the future**

There have been some promising steps to improve efficient eye care. For example, the Royal College of General Practitioners have made elderly eye health one of its four clinical priorities for 2013. This is certainly great but we need sure to focus on eye health of all ages.

There have been many Department of Health campaigns over the years. Smoking is a huge and obvious one. Yet it would be brilliant to see some of this effort directed to educating parents to get children's eyes tested, or highlighting the white reflex, or teaching people that failing eye sight can be a sign of serious diseases. Such Department of Health drives could reduce money spent on unnecessary treatments by improving earlier detection and prevention, improve statistics for vision loss and even aid children at school who are struggling due to poor eyesight. These are just a handful of positive outcomes from increased education.

We are encouraged to brush our teeth twice a day. Eat our five a day. Exercise appropriately. Why doesn't anybody ever say, "Go and have an eye test"? So these are my focuses. Better education about eye health, across the board, not just retinoblastoma-related. And of course, continued support of CHECT and other children's cancer charities that have become so familiar to me now.

It breaks my heart that any child should die from a disease as cruel as cancer but when that death is preventable, it makes it all the more harder to bear. It absolutely needs to change, and like Comic Relief, Band Aid and all the other big fundraisers do here in the UK to improve the medicine and education abroad, we need to highlight the serious situation, globally, regarding eye health.

The educational review in this issue seeks to embed this interview in perspective by exploring the differential diagnosis of infantile presentations with a 'white pupil' (leukocoria) and highlighting a structured framework clinicians can adopt when seeing a child with this important clinical sign. ■

### **References**

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