



Childhood Eye Cancer Trust
Fighting Retinoblastoma

Press release for National Eye Health Week

The majority of parents say they are concerned about their child's eye health yet only half (49%) have ever taken their child for an eye test with a medical professional, over and above a developmental check-up, a survey has revealed.

Commissioned by the Childhood Eye Cancer Trust (CHECT), the survey, conducted on the Mumsnet website with parents of children aged up to six, revealed most (79%) of those questioned felt sure or were probably sure their child's eyes had been examined as part of a routine developmental check, with 12% saying they didn't know if they had been checked, and a further 9% sure that they definitely hadn't been checked during developmental checks.

When asked, a total of 49% of parents stated they had proactively taken their child for an eye check with either an optician, GP, hospital doctor or health visitor, outside of a scheduled developmental check.

To mark the start of National Eye Health week (June 13 -19, 2011) The Childhood Eye Cancer Trust is urging parents to become more aware of their child's eye health and to educate themselves in the signs and symptoms of serious eye disease.

Of those parents surveyed, most (61%) had heard of eye cancer in children, or retinoblastoma, but 89% of those that were aware of it (55% overall) didn't know a great deal about it and few were aware of all the signs and symptoms.

Almost two in five (37%) weren't aware of the life-threatening disease at all.

More than three quarters of mums (77%) correctly noted that a white reflection in the pupil is likely to be a symptom of childhood eye cancer, while only 12% correctly said a squint or lazy eye could be a symptom. Less than half (48%) correctly thought that a change in the colour of the iris could also be a warning sign. One in five (19%) incorrectly identified a red reflection in the pupil as a symptom of eye cancer.

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Parents are relying on the media to provide them with vital information about Childhood Eye Cancer Trust for, with 46% becoming aware of childhood eye cancer through a national newspaper or magazine article and 37% through the internet. Just 4% had heard about it through a medical professional.

CHECT chief executive Joy Felgate said parents have a right to be informed about the signs to look out for. “Anyone can spot the signs of this disease, you do not need to be a medical professional – you just need to know what to look out for. The majority of our members had never even heard of this disease until their child was diagnosed with it.”

Retinoblastoma (Rb) is a rare, fast-growing eye cancer of early childhood, with around 40 to 50 new cases diagnosed each year.

It is often diagnosed in the later stages as the signs and symptoms of the disease go unrecognised. Consequently around 80% of children with the unilateral (tumour(s) in one eye) form of the disease will need to have an eye removed and endure the ongoing difficulties of living with an artificial eye.

CHECT hopes that by raising awareness of the disease it will lead to more cases being diagnosed earlier and less severe treatments for children affected.

Backed by Mumsnet, the Childhood Eye Cancer Trust has now launched a campaign and petition to get the NHS to publish more information on signs and symptoms of retinoblastoma in the Birth to Five book, Personal Child Health Record (red book) and on the NHS Direct website.

Carrie Longton, co-founder of Mumsnet said: “Children’s eye health is high on the agenda for Mumsnetters – as the survey results have shown - and many of our users have taken their children for eye tests already. However, only a few were aware of all the signs and symptoms of retinoblastoma which is why we wholeheartedly back the Childhood Eye Cancer Trust’s campaign for more information on this disease.”

Mrs Felgate added: "Retinoblastoma is a very treatable cancer but is often diagnosed too late to save a child's eye. This is often because parents don't have the information which could lead them to seek help earlier.

“It is vital that every parent is aware of what to look out for so that should their child, or perhaps a friend or relative’s child, display any of the signs of this eye cancer, they would recognise the need to seek urgent medical attention as early as possible. We feel the NHS has a duty to ensure parents are informed about the importance of eye health.”

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Case study

CHECT member and mother-of-five Katy Bishop has been fronting the drive for better information for parents after her baby son Owen's diagnosis was delayed by five months when his symptoms were dismissed as a simple squint.

Mrs Bishop, from Petersfield, Hampshire, said: "Had I been alerted to the symptoms I would have questioned Owen's squint, especially when I could see this unusual reflection in his eye – another classic sign of eye cancer - I would have acted much sooner. I use my red book and Birth to Five book all the time but there was nothing in there that could have led me to think for one second that there was anything seriously wrong with Owen."

Owen, who will be two in August, has been through six cycles of chemo and endless cryotherapy and laser therapy in the ongoing battle to save his sight, his eyes and, ultimately, his life.

Today marks the beginning of National Eye Health Week where eye care charities, organisations and health professionals from across the UK join together to promote the importance of eye health and the need for regular sight tests for all.

To support CHECT's campaign for more information in NHS publications, add your signature to their online petition at <http://www.gopetition.com/petitions/publish-signs-of-childhood-eye-cancer-retinoblastoma.html>

For more information on retinoblastoma and the Childhood Eye Cancer Trust visit www.chect.org.uk, email info@chect.org.uk or call 0207 377 5578. For regional case studies and press enquiries contact Julie Firth on 07974 348695.

For more information on National Eye Health Week visit <http://www.visionmatters.org.uk>

The Mumsnet survey questioned 1001 parents of children aged 0-6 online from May 13-18, 2011.

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Notes to the editor

1. Retinoblastoma (Rb) is a rare form of cancer which affects the retina of children, predominantly under the age of 5 years.
2. Statistically it affects approximately 1:20,000 live births each year. This can also be expressed as between 40 and 50 cases a year or about one child a week. It represents 3% of childhood cancers in the UK and affects children from all races and both genders equally.
3. There are many different treatments available in the UK and 98% of children treated will survive, however, in the developing world, the survival rate is much lower.
4. In about 45% of cases, the condition is heritable (with 55% non-heritable). A person who has had this form of Rb has a 50% chance of passing it on to their children. The retinoblastoma gene (Rb1) was the first cancer gene to be identified.
5. Rb can affect one (unilateral) or both eyes (bilateral) and there can be anything from one tumour in one eye to multiple tumours in both.
6. A majority of children with unilateral Rb have an eye removed (enucleation) because most cases are not picked up until the child is about two-and-a-half. By then the outward signs are visible to the naked eye. 80% of unilateral Rb patients will require enucleation and around 5% of children with bilateral Rb currently have had double enucleation (both eyes removed).
7. The six signs of Rb are: a 'white reflex' in the eye, like a "cat's eye" caught in the light; a squint; red, sore, swollen eye without infection; change in the colour of the iris; absence of red eye in one eye in a photo (note: there can be other reasons why this occurs but it is ALWAYS best to get it checked out) and deterioration in vision.
8. There are two specialist NHS retinoblastoma treatment centres in the UK, The Royal London Hospital and Birmingham Children's Hospital.
9. There are no known environmental risk factors for the genetic changes that lead to Rb.
10. A total of 1,001 parents who are members of Mumsnet completed an online survey hosted on the Mumsnet site between 13-18 May 2011. All respondents were parents of at least one child aged 0-6 years. Respondents with more than one child within that age range were asked to answer about their eldest within that range. Respondents could opt into a prize draw to win a £200 Marks & Spencer's voucher. The data has not been weighted.

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