



## Impact of an education program on late diagnosis of retinoblastoma in Honduras

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Plain-language summary written by Sandra Staffieri

### Purpose of the Study

Leukocoria (white pupil) is the most common early sign for retinoblastoma.

This study from Honduras in 2007 evaluated an awareness program for parents and community health workers to recognise and respond to seeing leukocoria in a child. The idea being, if diagnosis was more timely more children would survive.

### Short Summary of the Study

#### Why was the study done?

When retinoblastoma escapes the eye (extraocular retinoblastoma), a child's chance of survival is significantly reduced. The most common signs of extraocular retinoblastoma are proptosis (bulging eye) and signs of eye inflammation (red and painful eye).

In Honduras, as in many other low-middle income countries (LMIC), the number of children presenting with extraocular retinoblastoma was high. This was in part due to a lack of awareness of the significance of leukocoria, resulting in delayed diagnosis and poor outcomes. To reduce the mortality rate, an education program for parents and healthcare providers was developed and implemented.

This study sought to determine whether the education program improved survival in children with retinoblastoma.

#### What did they do?

From June 2003, With the support from the Ministry for Health, posters (Figure 1) and flyers were displayed in government health clinics and distributed to parents throughout the country.

Using photos to demonstrate leukocoria, the posters included a telephone number parents could call if they saw leukocoria in their child.



Figure 1 Poster for the Honduras Awareness Campaign



The cost of the posters and flyers was approximately \$2700 per year.

In addition to the posters, seminars about retinoblastoma were held for healthcare workers so that when a parent described observing leukocoria in their child, they would take notice and refer them urgently for treatment.

Additional efforts to raise public awareness included television and radio stories about retinoblastoma.

## What did they find?

The most important findings for this study were that AFTER the campaign: (Figure 2)

- 1) More children presented with leukocoria
- 2) No children presented with common signs of extraocular disease
- 3) More children presented with intraocular disease (meaning it was contained within the eye)

And most importantly:

- 4) Survival of children increased from 14% to 48%

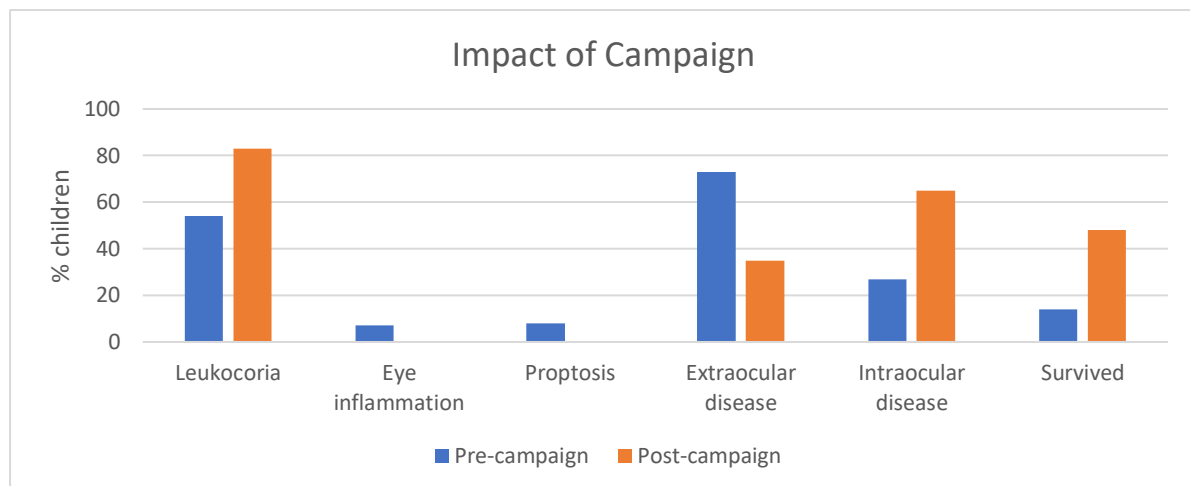


Figure 2 Main results of the study

## Conclusions of the Study

For the first time ever, this study documented the value of raising awareness of leukocoria.

Although the study also highlighted ongoing problems with treatment refusal and abandonment, it was a first step in showing that educating parents and healthcare providers alike is the first step in improving outcomes for children with retinoblastoma.

## **Personal Comment**

We have long known that the early diagnosis of retinoblastoma is the first step to saving children's sight, eyes and most importantly, lives. Even though worldwide many charitable organisations, hospitals and even individuals have been trying to



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raise awareness of retinoblastoma, there is very little published on the actual IMPACT raising awareness has had on outcomes.

It is evidence like this that will continue to support ongoing investment of awareness campaigns to diagnose retinoblastoma earlier and achieve better survival outcomes for children.

In the hope of reducing delayed diagnosis of retinoblastoma, this study underpinned my successful application for a prestigious government scholarship to develop and evaluate eye health information for parents about early signs of eye disease. Having demonstrated “If you tell them, they will know”, I have been able to successfully lobby my local health department to ensure parents receive this information when their child is born.