

The Model National Strategy for Developing Countries

will implement simple key changes that can dramatically reduce mortality in most developing nations.

For example, **raising awareness** of the signs, and that infants can have cancer, will increase early diagnosis; introducing **expert pathology** assessment of surgically removed eyes will optimise resources for children who require further treatment; introducing **child life** approaches will improve patient welfare and minimise treatment costs, and developing **family support** services will reduce abandonment of both treatment and child.

We have begun working with doctors, local and national business community members, NGOs and community leaders in **Kenya** to establish a model sustainable National Retinoblastoma Strategy (NRbS) for resource-limited countries.

Our GRbS projects will facilitate many important changes that can rapidly shift global survival and vision outcomes closer to those already achieved in resource-rich countries. Death and blindness from retinoblastoma *can* be substantially reduced around the world, without additional expensive resources.



HOW YOU CAN HELP

- ❖ Help us with ongoing fundraising or promotional activities, or make a personal financial gift.

Daisy's Eye Cancer Fund relies entirely on charitable gifts to carry out our vital life-saving work. Please join our fundraising team or make a donation today and help give children with eye cancer hope for a brighter future.

If you are a UK tax payer, we will be able to claim 28p Gift Aid back from the tax man for every £1 you donate.

Please contact us for a Gift Aid form, or for more information about making a regular contribution by Standing Order. This will help us to plan ahead with confidence.

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HELP US MAKE A LIFELONG DIFFERENCE
TO CHILDREN WITH EYE CANCER



Daisy's Eye Cancer Fund
A Global Response To Childhood Retinoblastoma



Global Retinoblastoma Strategy

Because "eye cancer" is two words,
not a sentence.

Registered Charity Number: 111-11-33.

WHAT IS RETINOBLASTOMA?

Retinoblastoma (RB) is a fast growing eye cancer of early childhood. The most common sign of this cancer is a white pupil, like a cat's eye, that can be seen in low light or flash photography



When contained completely within the eye, retinoblastoma is 100% curable with correct treatment and follow-up. However, without early intervention, the cancer quickly spreads to the brain or bone marrow, with very poor prospects for cure.

World Retinoblastoma

96% of children are cured in developed countries today, many retaining useful vision. However, 92% of affected children live in less economically developed countries, where awareness and resources are limited. Consequently, global survival is only 20%. In some countries this may be lower than 10%.

The majority of children in resource-poor countries are diagnosed at an advanced stage, and many children may die before diagnosis. Most advanced and fatal cases are observed in rural, underprivileged communities. The main causes of late diagnosis are lack of access to health care information and informed health care providers, widespread illiteracy and principal use of traditional medicines.

Treatment of curable children is often abandoned due to the financial burden of mounting transport and accommodation costs, and lack of family support services.

RATI'S STORY

Aged just 11 months, Rati's cancer-filled left eye was removed in her home country of Botswana.

Doctors believed the surgery had cured her. However, delayed diagnosis, incomplete treatment and lack of follow-up led to a recurrence in the eye socket 19 months later, which her doctors could not treat due to lack of training and treatment facilities.

With support from around the world, Rati was able to receive expert care at Toronto's SickKids Hospital, giving her the best chance of a cure. However, this support came



too late for Rati, and she died in August 2006, aged 4 years. Had Rati received proper care when she was first seen by doctors at 5 months old, she would be alive and well today.

Rati set us the challenge of improving care for children in developing countries so that, one day, no child would have to face death because of late diagnosis or inappropriate care. Daisy's Eye Cancer Fund (DECF) was founded to work towards that goal.

We are the world's only charity dedicated to improving care, and access to that care, for all children with retinoblastoma, regardless of their personal circumstances.

A GLOBAL APPROACH TO CURE

We are currently developing a Global Retinoblastoma Strategy to help optimise available resources around the world. The strategy consists of four projects, each of which is based on innovations that have emerged from global collaborations of parents, patients, survivors and professionals.

Design of best practice guidelines will ensure fast tracked referral, access to optimal care at specialist centres, and supportive care for the affected child, carers and the whole family unit. Guidelines already developed in the UK and Canada will be adapted for use in diverse settings around the world.

The World Retinoblastoma Registry will achieve a fuller understanding of global retinoblastoma patterns, assess access to care, response to available therapies, and empower appropriate application of resources.

The World Research Group will overcome challenges posed by the small numbers of children cared for at hospitals widely dispersed around the world. Clinical trials are the only way to effectively measure success of specific cancer therapies..

The World Research Group will improve our ability to validate approaches to care, and will promote new opportunities for collaborative work at a global level.

