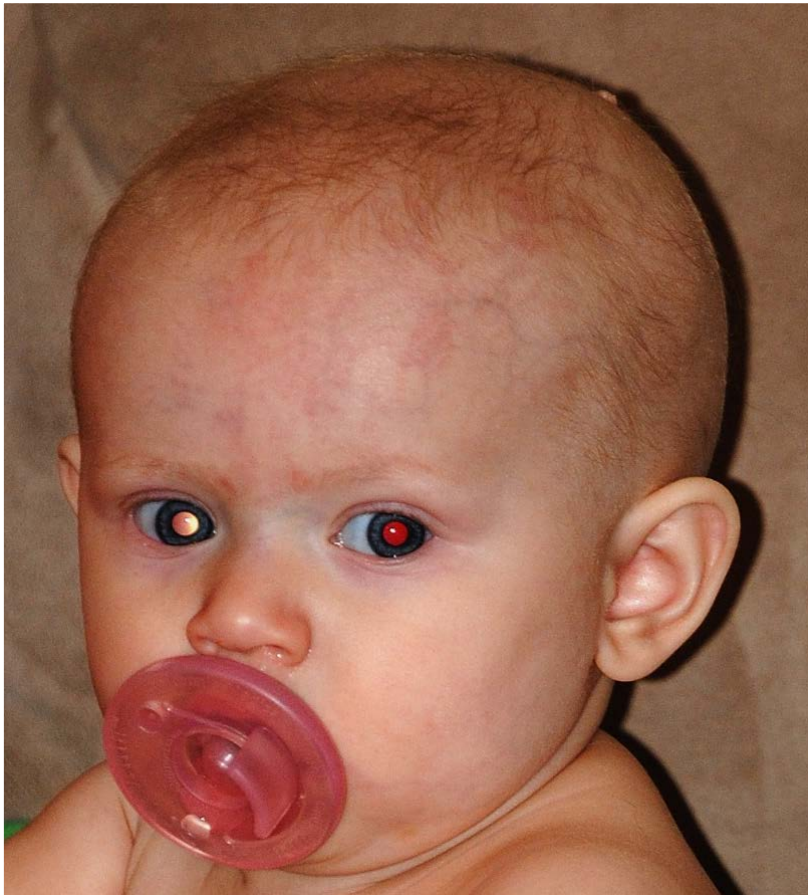




World Eye Cancer Hope
life and sight for every child

www.wechope.org



“When Spiders’ webs unite,
they can tie up a lion”

Ethiopian proverb

World Eye Cancer Hope USA

Building Hope For All Families In America

America has some of the best retinoblastoma specialists and facilities in the world, but many families struggle to access high quality medical care and emotional support. We bring hope to children, families and survivors across the country.

About two hundred and eighty children develop retinoblastoma each year across the USA. Overall, survival is above 95%, but is lower in the African American population.

Around 90% of children are diagnosed as a result of family members observing a white glow in the affected eye/s. Most families have stories of late diagnosis due to lack of action when they first raised concerns with a primary health professional.

A handful of retinoblastoma centers are scattered across the country, located in eye centers, children's hospitals and specialist cancer centers. There is no coordinated research among them. Many other hospitals treat fewer than five children per year.

Major challenges to effective care are:

1. late diagnosis, when removal of the eye is the only option to save the child's life;
2. no agreement on best treatment, creating confusion and hindering informed consent;
3. emotional, practical and financial burdens that isolate and overwhelm the family.



Nationally coordinated awareness and care will improve opportunities for children with Rb

Our Mission

Nationally co-ordinated early diagnosis and referral campaigns, evidence based medical care and practical, compassionate support will reduce many of the burdens families face, and increase opportunities to save children's eyes and sight, as well as their precious young lives. This is our mission.

Retinoblastoma Family Groups: we aim to develop single-state and regional family groups across the country, so that every family will have access to face-to-face support close to home. Each group will offer social activities, information for families, a small grants fund and local advocacy.

National Retinoblastoma Strategy: we aim to develop a national collaborative multi-center approach to retinoblastoma care, encompassing early diagnosis campaigns, evidence based medical care and family support initiatives to enhance care for all affected children, survivors and their families.

We felt so alone when our son was diagnosed. The hospital provided excellent cancer care but they weren't familiar with Rb and it was a tough road. I wish we'd had more support.

~ Mother of child in Colorado ~

The challenges we face are significant, but by working together across the country, with the child and family at the heart of all we do, we can build for them a bright future.

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World Eye Cancer Hope USA

Retinoblastoma Care In America Today

Poor awareness, lack of nationally coordinated medical care and poor support leads to unnecessary stress and suboptimal outcome for many families. Simple change can make a huge difference.

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Awareness of retinoblastoma among both parents and medical professionals is very limited. This leads to delayed diagnosis, slow referral to specialist care and often delays in treatment while families explore alternatives to eye removal surgery.

Medical care is hindered by lack of multi-center clinical trials, limited evidence about the best treatments, and lack of guidelines for management of children and families.

Lack of support causes families to feel isolated and overwhelmed, especially when facing removal of their child's eye, or coping with retinoblastoma's lifelong implications.

The doctor didn't listen when I saw my son's eye glowing white. When he was finally diagnosed, we struggled to find good care and he lost both eyes. Our story could have been so much better.

~ Mother of child in Idaho ~

The challenges facing retinoblastoma care in America are significant, but there is also vast opportunity to overcome many of the hurdles with simple change and collaborative effort that puts the child and family first, always.

Early diagnosis, nationally co-ordinated care and practical, compassionate family support, will reduce many of the burdens families face, and will increase opportunities to save children's eyes and sight, as well as their precious young lives.

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World Eye Cancer Hope USA

Life-Saving, Sight-Saving Awareness

Early diagnosis of retinoblastoma is a child's only hope for healthy vision in America. We will raise awareness to increase early diagnosis and rapid referral to specialist care.

The Challenge

There is little awareness of childhood eye cancer among the public or primary health workers in across the USA. Early diagnosis is hampered by limited access to informed health care providers, lack of guidelines on appropriate action for children with "white pupil", and ad hoc referral to specialist care.

A white pupil and squint are the only visible signs of retinoblastoma in its early stages. Most families do not seek medical care until the cancer is a severe threat to life and sight.

Removal of the affected eye(s) is often the only option to protect the child's life. Late diagnosis severely reduces the opportunity to save sight when both eyes are affected.

Intensive therapy required for retinoblastoma that has spread beyond the eye places huge burdens on the family, with very poor chance of the child's survival.



White pupil is the most common early sign of retinoblastoma – awareness saves lives!

Our Solution

We will develop a national campaign to educate the public and primary health care workers about retinoblastoma. Focusing on the most common early sign of white pupil, and the need for prompt treatment to save life and sight, we will work with national and state agencies to:

include "white pupil" information in Child Health booklets given to new mothers;

advocate newborn eye screening and **red reflex eye exams** at well child visits;

send educational posters to pediatrician offices, child health clinics and immunisation centers, in collaboration with existing state and federal programs;

secure prominent media coverage (print, TV and radio) of retinoblastoma, featuring children's stories and interviews with medical professionals, parents and survivors;

include educational seminars at continuing medical education events, to inform medical professionals about eye cancer in children.

These simple strategies will help to detect retinoblastoma in the home and clinic, before it destroys vision or spreads beyond the eye.

Earlier diagnosis will dramatically increase a child's chances of cure and prevent the great suffering caused by advanced disease. Cost of treatment will also be reduced, relieving financial burdens on the family.

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World Eye Cancer Hope USA

Effective Medical Care For Every Child

Children with retinoblastoma require highly specialised care. We advocate for national Rb management guidelines and agreed treatment protocols that promote best possible medical care.

The Challenge

Life-saving therapy exists across America, and many centers have the capacity to save eyes and sight. However, lack of agreed therapy and follow up causes many children and families to suffer needlessly.

The main challenges to effective medical care in America are:

no management guidelines, leading to unequal care and confusion among families;

no agreement on high risk pathology indicators, leading to over- and under-treatment after eye removal surgery;

no collaborative clinical trials and limited evidence to support treatment options;

lack of clear information for families and survivors, preventing them from making informed decisions about medical care.

no national Rb patient database, hindering care and clinical research.

Our Solution

Our US National Retinoblastoma Strategy (USNRbS) aims to unite doctors, nurses, parents, survivors, health advocates and community leaders to build sustainable awareness and evidence based medical care for children, survivors and their families.

The USNRbS will identify available resources, gaps in care and knowledge, and major challenges to life and sight survival.

We will work together to develop solutions, and advocate their implementation to bring common standards of care to children, survivors and families across the country.

Annual USNRbS meetings will underpin the national strategy, promoting creativity and leadership, collaborative development of solutions to advance care and cure; and enabling effective ongoing evaluation of performance and success every year;

Hope is the quiet joining together of many hands, hearts and minds in patient collaborative effort to provide the very best care possible.

~ Parent of a child with Rb in Kansas ~

Some solutions will be quickly introduced. Others will require patience, determination and teamwork over many years. Together, they will create a sturdy national approach to retinoblastoma that protects children's lives, improves opportunity to save their sight and enhances quality of life for the whole family.



Nationally coordinated care will make a huge difference to children and their families.

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World Eye Cancer Hope USA

Compassionate, Practical Family Support

A child's chance of cure is affected by their overall mental and physical wellbeing, and that of their parents. Retinoblastoma Family Groups promote good quality of life for the whole family.

The Challenge

When a child is diagnosed with cancer, they and their family are thrust into a world of challenge, uncertainty and fear.

Families across America can access a range of services, such as cancer information, hospital housing, support groups, child life specialists, wish-granting, camps, holidays, gift-giving programs and hospice care.

However, a retinoblastoma diagnosis brings unique experiences that demand a support program specifically designed for Rb families.

"We felt so alone when our son was diagnosed – I wish we'd met with other families who understood our fears."

~ Parent of an Rb survivor in Texas ~

The main challenges for families are:

lack of an organized system to connect families with one another so they can meet socially for mutual support;

financial burdens of medical bills, frequent hospital visits, loss of income and essential care items not covered by health insurance;

no sustainable awareness campaigns and organised advocacy activities at national and state level, hindering high quality care.

These challenges cause extreme suffering for children and their families, loss of sight and eyes that might have been saved, and sometimes even death of the child.

This toll of suffering is entirely preventable!

Our Solution

Many of the challenges families experience can be overcome with simple solutions. We will develop Retinoblastoma Family Groups across the country, so that all families will be able to access Rb-specific support close to home. Each Group will offer:

A program of social activities enabling parents, children with Rb, siblings, survivors and other family members to connect in a relaxed environment away from the hospital;

A small grants fund offering assistance to families in financial need;

Opportunities for local advocacy as part of our state and national level awareness and medical care promotion activities.

An annual convention will unite groups from across the country to share knowledge, information and support and encouragement.



A comprehensive family support system may take years to develop, but it will strengthen care for the child and entire family. In the process, the many burdens they face can be eliminated or significantly reduced.

www.wechope.org/usa



Fundraise For WE C Hope

Be a Fundraising Angel and Save a Child's Life!

Our programs are entirely funded by donations. With your help, we can increase awareness, access to medical care and family support, and save thousands of precious young lives.

How Your Money Helps

\$25 funds a support pack for a family facing life saving removal of their child's eye.

\$75 buys 500 posters to educate about the early signs of retinoblastoma.

\$150 funds a social activity, enabling families to meet, relax and encourage one another.

\$750 funds a therapeutic art day, helping 75 children while raising awareness and funds.

\$1,500 enables 2 families to attend a national weekend retreat and educational program.

\$2,260 funds a local family group for 1 year, delivering practical and emotional support.

\$7,500 funds a full time program manager in a developing country for 1 year.

\$25,000 funds a 3 day meeting for families survivors and medical professionals to build collaborative, inclusive evidence based care.

Taking Care of Your Gift

We take great care to apply donations where they are needed most. We strive to keep our admin, marketing and fundraising costs well below 20% of annual expenditure and aim to reduce this further as we grow..

Our teams in the UK, USA and Canada are all dedicated volunteers, so we can ensure maximum impact from limited funds.

*Because of care from WE C Hope,
Hope for mummy, daddy and me,
Because of your donations
I'm alive and cancer free! .*

From "My Story" – the experience
of a child with retinoblastoma.

Fundraiser Resources

There are many ways you can help us achieve our goal of essential life and sight saving care for all children with eye cancer and survivors, and support for their families.

Fundraising can be very rewarding and great fun, but also daunting if you've never done it before. Fundraiser resources on our website will guide you through planning and help you host a successful, enjoyable event.

Resources includes an A to Z of 60+ great fundraising events, a detailed planning guide and a media toolkit to help you gain publicity.

Find out more and download resources today
at www.wechope.org/give-hope/fundraise



Rb survivor, Alison Wadge, and her friends sell home-made jewellery to raise funds.



Donate to WE C Hope or Contact Us

Make a Life Saving Difference Today!

However large or small, your gift will bring life and sight saving care to children with eye cancer around the world, hope to their families and essential resources to the people who care for them.

Donate Online

Giving online is quick, easy and instant. You can donate with PayPal or a credit or debit card, and will receive an email tax receipt.

You can opt to make a one off or recurring (weekly, monthly or annually) donation, or create your own fundraiser page to engage friends and family in giving.

Donate to WE C Hope USA

<http://www.wechope.org/usa/donate>

Donate By Check

We can receive US\$ checks only. Please pay "World Eye Cancer Hope" and mail it to our address below, including your full mailing address so we can thank you.

Contact Us

Please contact us with any enquiries. We welcome all, feedback and look forward to hearing from you as we continue to develop activities to effectively meet current needs of all families affected by childhood eye cancer.

World Eye Cancer Hope
5640 Telegraph Road, Suite 306
St. Louis, MO 63129

Email: usa@wechope.org
Telephone: (314) 669-1104 (this is an voicemail, we will return your call).

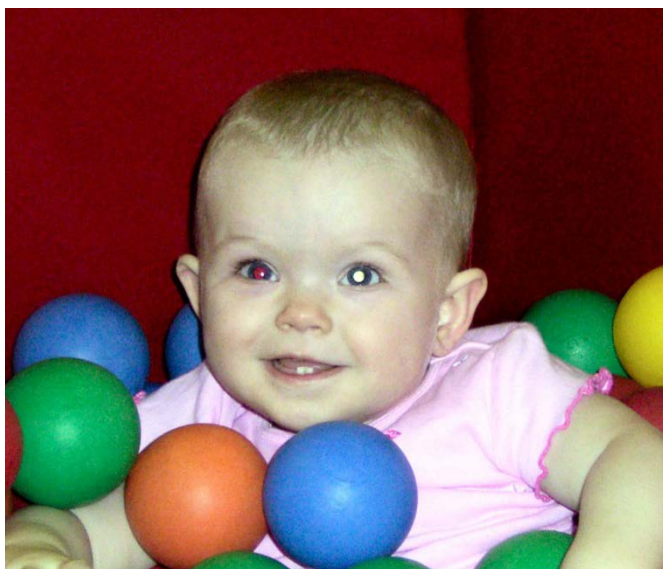
Concerned About a Photograph?

If you have seen a white glow in the photo of your child, or with your naked eye in dim light, please seek a prompt red reflex eye exam from your primary doctor, or request an appointment with an ophthalmologist.

Use the photography technique described in the poster included in this pack, to check for normal red reflex. If the pupil does not show red reflex, or glows white in several photos taken with this technique, seek an urgent (within 72 hours) dilated eye exam from an ophthalmologist (eye doctor).

With early diagnosis, appropriate treatment and follow up for both eyes, children have an excellent chance of cure.

Untreated retinoblastoma kills children.



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