



Notes for Editors - World Eye Cancer Hope

Our History

- World Eye Cancer Hope was inspired by Daisy Lloyd, an English schoolgirl who was diagnosed with cancer in both eyes at the age of 13 months in 2000.
- When all treatment options failed to kill the cancer, Daisy's family took her to Canada for treatment that was unavailable in England, hoping to save her last eye. They created The Daisy Fund to fundraise for her medical care in Toronto.
- On their return to England, Daisy's family helped an African child whose cancer relapsed outside her eye. They donated money from The Daisy Fund to pay for travel to Canada and initial treatment to give two-year-old Rati the best possible chance of cure.
- Daisy's Eye Cancer Fund was founded in 2004 in England and Canada to raise funds for Rati's treatment, which included bone marrow transplant.
- Rati was in remission for a year, but when her cancer relapsed, no more treatment was possible. When she died on 21 August 2006, we broadened the mission of Daisy's Eye Cancer Fund to tackle the challenges that robbed Daisy of her sight and Rati of her life.
- The organization rebranded in September 2015 to become World Eye Cancer Hope, reflecting our global vision of life and sight for every child.
- Our shortened name is WE C Hope.

Our Chapters and Partners

WE C Hope has three Chapters and one major country partner. Each is an autonomous organization with shared vision, mission, values, programs and identity.

- Canada: University Health Network, Toronto General and Western Hospital Foundation.
- England: Registered Charity #: 111-11-33
- USA: 501(c)(3) National Non Profit. EIN: 45-4886827
- Kenya: Our partner, the Kenya Childhood Cancer Trust, is a Registered NGO.

Our Vision and Mission

- The vision of World Eye Cancer Hope is to achieve life and sight saving care for every child with retinoblastoma, survivors and their families around the world, regardless of their personal circumstances.

- In our mission to achieve this goal, we:
 - Educate the public and primary health workers about retinoblastoma to achieve early diagnosis and rapid referral to specialist care;
 - Empower the medical community to deliver sustainable high quality evidence-based care that gives each child and survivor the best possible opportunities;
 - Enable family support programs that reduce practical, emotional, financial and social burdens and improve access to essential care.
- All our team members In Canada, the UK and USA are full time or part-time volunteers.

Rati's Challenge

- In September 2006, we launched Rati's Challenge to address the needs of families affected by retinoblastoma in Africa. The Kenya National Retinoblastoma Strategy was launched through this program in September 2008, to build a model for capacity building and sustainable care of children in developing countries.
- We work in full collaboration with the Kenyan government in developing the first fully national collaborative program to improve retinoblastoma care in a low income country.
- We have added information about the early signs of childhood eye cancer to the Mother and Child Health booklet, which is produced by the Ministry of Health and given to parents, primary health workers and paediatricians across the country.
- We have trained ophthalmologists and oncologists in the best techniques and treatment regimens for care of children with eye cancer.
- We have trained East Africa's first specialist ocular and orbital pathologist, and established / equipped the Rb Collaborative Laboratory in Nairobi. Precise pathology of removed eyes guides post-operative care and maximises the use of limited resources.
- We have developed provision of artificial eyes that are vital to rehabilitation and even acceptance of surgery when a child's eye must be removed to save their life.
- We have donated a Retcam™ to Kenya to enhance eye examination and treatment, aid training and enable online consultation (telemedicine) to benefit patient care. This is standard equipment at Rb treatment facilities in Canada, the UK and USA, but our donation was the first Retcam in Africa.
- We led development of collaborative national guidelines for retinoblastoma care, which have been endorsed by the Kenyan government and are in process of implementation.
- We created a handcrafting program at Kenyatta National Hospital in Nairobi and Moi Hospital in Eldoret, enabling parents to generate income while their child receives treatment. This empowers them to pay premiums for the National Hospital Insurance Fund, which covers the cost of inpatient medical care. The program also lifts the spirit and gives parents a healthy distraction, reducing their risk of abandoning treatment.
- We are training medical professionals and family advocates as child life leaders, to deliver family-focused care that reduces emotional distress and lifelong negative effects.

World Eye Cancer Hope USA

- Daisy's Eye Cancer Fund USA was founded in January 2012. The organization rebranded in September 2015 to become World Eye Cancer Hope.
- As well as supporting vital international work, sharing hope with children and families worldwide and improving global survival, WE C Hope USA has two national goals:
- **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 family group will provide a program of social activities, Rb information, a small grants fund for families in need, and local advocacy.
- **National Retinoblastoma Strategy:** we will lead development of a national collaborative approach to retinoblastoma care, encompassing awareness campaigns, evidence based medical care and family support initiatives to improve care for all affected children, adult survivors and their families in America.