Rati’s Challenge: Retinoblastoma in Africa

Report of Visit to Kisumu, Kenya

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ABOUT THE AUTHORS

Brenda Gallie
Dr Gallie is a professor in the University of Toronto’s Department of Medical Biophysics, Medical and Molecular Genetics and Ophthalmology, and the Hospital for Sick Children Research Institute, where she is also Director of the Hospital’s retinoblastoma program. She is Head of Cancer Informatics at the Ontario Cancer Institute, Princess Margaret Hospital and scientific director of Toronto Hospital’s Eye Research Institute. She co-founded Daisy’s Eye Cancer Fund in 2004.

Abby White
Abby White is a survivor of bilateral retinoblastoma. Her father was diagnosed with bilateral retinoblastoma in Nairobi, Kenya in 1946, and treated in London, England. Abby studied geography at university, with a special emphasis on development in sub-Saharan Africa. She co-founded Daisy’s Eye Cancer Fund in 2004, and co-ordinates the organisation’s activities in the UK.
Childhood cancer accounts for a small proportion of the world's cancer burden, yet progress in the care of children with cancer over the past 40 years has led to dramatic improvements in survival. Despite the fact that one child in five hundred will develop cancer before the age of 15, two out of three youngsters treated at paediatric cancer centres in developed countries now survive, and the success rates are continually rising.

However, these improvements have also exposed huge differences in treatment and outcome for children in resource rich nations and those with limited resources. Roughly 92% of children with retinoblastoma live in economically less developed countries, where diagnosis often comes too late for effective treatment, and appropriate management of the cancer is frequently unavailable or too expensive. While 96% of children survive retinoblastoma in developed nations, the global survival rate is only 20%, and in some African countries, it may be lower than 10%.

Simple changes could make a big difference to the survival and wellbeing of affected children and their families in resource poor countries. Our work in Africa has only just begun, yet with no money and in a short space of time, awareness of retinoblastoma has already increased in Kisumu, Kenya. Early diagnosis is the key to successful treatment.

The challenges facing paediatric oncology care in Africa are significant, but the potential for improving care of children with retinoblastoma is also great. Now is the time to begin working towards a day when no child has to face death from this easily recognisable and highly curable cancer.
AN INTRODUCTION TO RETINOBLASTOMA

Retinoblastoma is a rare, fast growing eye cancer of early childhood. It may affect one or both eyes, and typically develops before 5 years of age. Some children are born with tumours.

Retinoblastoma occurs in between 1:15,000-20,000 live births. Consequently, countries with very high birth rates, such as India, experience a significantly higher incidence of retinoblastoma than countries with low birth rates. Many of these countries are situated in the developing world, and we estimate that 92% of children with retinoblastoma live in economically less developed nations.

The most easily recognisable sign of retinoblastoma is the white reflection seen in the pupil, called “leukocoria”. The tumour in the eye reflects light, like a cat’s eye at night, when light shines into the child’s eye from close to the observer’s head. Leukocoria can also be seen in photographs where a flash has been used. With good awareness among the medical community and general public, the diagnosis of retinoblastoma can be made easily, and lives saved through early medical intervention.

Treatments include laser, cryotherapy (freezing the tumour), systemic and focal chemotherapy, brachytherapy (radioactive plaque sewn on the surface of the eye above the tumour), radiotherapy and enucleation (surgical removal of the eye). However, in many developing countries, enucleation remains the only available treatment.

Retinoblastoma is a potentially blinding and fatal cancer, but it is also one of the most curable cancers in children. However, without early intervention, the cancer will quickly spread beyond the eye, travelling directly to the brain, or invading the bone marrow. While more than 96% of children survive retinoblastoma in developed countries like the UK and Canada, approximately 80% of children around the world will die. In Africa, the survival rate may be less than 10%.
During the 2000 World Summit Against Cancer for the New Millennium, organisations from around the world adopted the Charter of Paris, acknowledging that improved access to currently available drugs can prevent the majority of cancer deaths around our world. The Charter calls for “an invincible alliance – between researchers, healthcare professionals, patients, governments, industry and media – to fight cancer and its greatest allies, which are fear, ignorance and complacency.”

Daisy’s Eye Cancer Fund was established in 2004 in Oxford, UK and Toronto, Canada, inspired by 4-year-old Gorata (Rati) Poonyane. Rati died because of delayed diagnosis and incomplete treatment in her home country of Botswana. Her cancer-filled left eye was removed when she was just 11 months old, and doctors believed the surgery had cured her. However, when the cancer recurred in the eye socket 19 months later, her doctors could not treat her due to lack of training and treatment facilities.

Rati’s parents, John and Salome, turned to the Internet for help, sending out an email request for prayer and advice. Retinoblastoma survivor Abby White in Oxford, England immediately responded, using her contacts in the worldwide retinoblastoma community to find help for the sprightly little girl.

With donations from around the world, Rati was able to receive expert care at Toronto’s Hospital for Sick Children, giving her the best chance of a cure. However, this support came too late for Rati, who died in August 2006. Had Rati received proper care when she was first diagnosed, she would be alive and well today.

Daisy’s Eye Cancer Fund (DECF) was established to begin to address the needs of children around the world like Rati, who struggle to access appropriate retinoblastoma health care. The DECF now works to improve awareness and access to essential care for retinoblastoma children, when and where it is needed.

Our strength lies in the worldwide collaboration of health care professionals, parents and patients, scientists and others who are concerned about retinoblastoma. Our long-term goal is to achieve sustainable, locally-administered diagnosis and treatment programs for retinoblastoma, optimised for diverse regions of the world.

Mortality has been 4% in developed nations for many years, yet across Africa, mortality is as high as 90%. We set out to investigate the issues faced by affected families and their health care professionals. We examine the possibilities of developing a specialist regional treatment program within East Africa. This report documents the findings of the DECF initial visit to Kenya in Autumn 2006.
AN INTRODUCTION TO KENYA

Geography
Kenya straddles the equator, covering an area of 583,000 sq km (225,096 sq miles) between the humid Indian Ocean and Lake Victoria. The cool, fertile Rift Valley and Central Highlands provide the backbone of Kenya’s predominantly farming economy. To the north and south, vast deserts and savanna remain largely untouched, teeming with wildlife and maintaining the vital tourist industry. However, challenges posed by the environment are great - the worst drought in a decade grips western Kenya, whilst the coast has recently been tormented by the most appalling floods in 50 years.

Borders are shared with Sudan, Ethiopia and Somalia to the north, Uganda to the west and Tanzania to the south. As a result of this central location in East Africa, the capital city, Nairobi, has developed as a major transport and financial hub, and the base for most aid agencies working in the region.

People
Kenya has a population of 34,700,000, and with 43% of the population aged under 15 years, the country has a projected population increase of 87% by 2050. There are more than 70 tribal groups, but just 7 tribes account for 84% of Africans in Kenya. Western cultural attitudes are eroding traditional values, and tribal distinctions are blurring. However, an individual’s tribal origin is still sacred, reflected in the practice of always asking new acquaintances which tribe they are from. Inter-tribal violence and banditry is a sporadic problem in several regions of Kenya, particularly in the north, and along the north-west borders, but generally different communities exist harmoniously across the country.

English and Swahili are taught throughout the country, and English is the official language of school education. However, there are many tribal languages. Observance of traditional customs means women marry much younger than men. 20% of 15-19 year old girls are married, compared to just 2% among men. As a result, high school attendance among girls is significantly lower than attendance for boys. However, the literacy gap between men and women is relatively narrow.

65% of the population is Christian (35% Protestant, 30% Roman Catholic), 30% Muslim and 5% Animist. The Christian churches play a major role in dissemination of health information across the country, through poster campaigns and circulation of magazines.

Kenyan babies of many shapes and sizes are greatly loved.
Government

Kenya’s history dates back more than 2000 years to the ‘cradle of humanity’. A long succession of invaders, sultanates and colonisers ended in 1963 with independence from the UK. Independence President, Jomo Kenyatta developed the country into one of Africa’s most stable and prosperous nations. However, the presidency of his successor, Daniel Arap Moi, was dogged by nepotism and dissent. This led to major rifts and much corruption, destruction of tribal societies and harassment of opposition politicians and supporters. The International Monetary Fund (IMF), the World Bank and other major donors eventually suspended aid in the early 1990s, demanding this repression cease. However, due to splits in the opposition party, Moi won the 1993 and 1997 election with less than 40% of the vote. He retired with very favourable benefits in 2002, after 24 years in office.

The subsequent election was won by the opposition National Rainbow Coalition, led by Mwai Mbaki. However, political disharmony continues with the new government as the British High Commissioner laid serious corruption allegations against the ruling party in 2005. This resulted in aid suspension by the Netherlands, Germany and USA, and threats of aid suspension from the EU and Japan. This situation, compounded by allegations of media censorship, has not been fully resolved at the time of writing.
Kisumu is the administrative centre of Nyanza Province in Western Kenya. This is Kenya’s third largest city, with a population of approximately 400,000, and a fast developing business community. Many churches, mosques and schools can be found here, as well as the Kisumu District Hospital, New Nyanza Provincial Hospital, Centre for Disease Control and Aga Khan (private) Hospital. Nyanza Provincial is the largest public hospital outside Nairobi, and one of only four provincial hospitals in Kenya currently able to provide care for children with cancer (the others being located in Nairobi, Eldoret and Mombasa).

Nyanza takes its name from the Swahili word for Lake, and the province borders Lake Victoria, which is Africa’s largest fresh water lake and source of the White Nile. Kisumu is Kenya’s main lake port, with infrequent, unreliable links to Tanzania and Uganda. The lake is a rich source of tilapia and nile perch. Fishing and boat-building used to flourish here, but water hyacinth has driven the fish far away from shore, and almost choked the life out of both industries. Steps have been taken in recent years to clear inshore waters of the weed, but it will be many years before the small scale fishers and boat builders recover.

Kisumu’s surrounding green hills and fertile lowlands are the most densely populated rural areas in Kenya. Commercial farming in the province is limited primarily to sugar cane, and the majority of farming activity is carried out at a subsistence level. Bananas, cassava, millet and maize (corn) are the main crops. The staple food is ugali, a starchy dish made from either maize or millet. This is often eaten with beans or a meat sauce - maximum nourishment at minimum cost. Many schools grow crops in their grounds to help feed the students and raise funds through sale at market.

Most people in Nyanza wear western clothes, but preserve traditional customs of dress, music and dancing for special ceremonies. In rural areas, most houses are a single room construction, consisting of a round wooden pole frame and mud walls, with a pointed thatch roof. At night, cattle are brought into a protective enclosure around the homestead. Euphorbia bushes are usually used to form the enclosure because they have no leaves, but their milky juice would be poisonous to any potential wild animals.
In 2005, during a personal visit to friends in Kisumu, Kenya, DECF co-founder, Abby White visited the city’s Provincial Hospital to see how children with retinoblastoma are cared for in the region. Abby discovered retinoblastoma to be the second most common malignancy observed in western Kenya, yet the care for these children – and all children with cancer at the hospital – was limited and inconsistent.

Following Abby’s visit to Kisumu, we established Rati’s Challenge, a DECF campaign to improve care for children with retinoblastoma in Africa. We began to examine Kenya’s health care system in the wider context of Africa, and the feasibility of investigating retinoblastoma care in Western Kenya as an example of the African experience.

Under the strain of HIV/AIDS and other communicable diseases, most countries in Africa are struggling to maintain a working health care system. Kenya is not without massive challenges.

However, many indicators point to a relatively stable health system that is likely to be capable of developing effective structured programs for paediatric sub-specialties such as oncology. A few of those indicators are discussed here.

**HIV/AIDS**

Sub-Saharan Africa continues to face an HIV/AIDS crisis. The health care system in many countries is being crippled by the burden of this disease. Three of the world’s highest HIV prevalence rates are recorded in the wealthiest countries of southern Africa (South Africa, Swaziland and Botswana). In these wealthier countries, HIV/AIDS tends to reverse any efforts made to reduce child mortality. This is because parents, other relatives and health workers cannot care for sick children when they are ill themselves due to HIV infection. That lack of adult care leads to child malnutrition, loss of early paediatric health care intervention and young orphaned children raising their siblings – all of which increases the numbers of children at risk from early death.

Kenya is a wealthier country by African standards. However, the incidence of HIV/AIDS is much lower than in many African countries, at around 7%. While many African health care systems are beginning to collapse under the burden of HIV/AIDS, Kenya’s health service remains relatively stable.
Infant and child mortality

42% of global child mortality occurs in sub-Saharan Africa, and according to the World Health Organization (WHO), four million African babies per year die in the first week of life. Infections and diseases are the main child killers: cholera, hepatitis, meningococcal meningitis, typhoid, tuberculosis, HIV/AIDS, measles, malaria, tetanus and others. However, the majority of these deaths are preventable through simple measures such as strengthening the infant immune system through breastfeeding, immunising children against disease, and increasing the use of mosquito nets.

In 2000, the United Nations established seven Millennium Development Goals (MDGs) to improve quality of life around the globe. The fourth MDG aims for a two-thirds reduction in child mortality, from 93 deaths per 1,000 under five year olds in 1990 to 31 per 1,000 in 2015. Massive investments are now being made to reduce preventable deaths from infectious disease, and Kenya is one country where progress is being made.

Breastfeeding rates and access to post-natal care are slowly improving across Kenya, showing that improved knowledge does change practice. The United Nations Fund for Population Activities (UNFPA), together with the World Health Organisation is addressing the health of mothers as well as newborns, and the numbers of babies surviving into childhood is likely to steadily increase over coming years.

One of the MDG Child Mortality targets is the increase of immunisation coverage to at least 90% at national level and 80% in all districts by 2015, with a particular focus on eradication of polio. Kenya is well on the way to meeting that target, with a current national polio Immunisation coverage of 73%.

Another of the MDG Child Mortality targets is to increase the number of children sleeping under mosquito nets to at least 60% in malaria-endemic areas by 2015. Mosquito nets help reduce malaria, an infection which is responsible for 10% of all under-five deaths in developing countries. Kenya currently has a national net usage of 15% in the under-five age group. However, it should be remembered that malaria does not occur in the higher lying areas of Kenya, and it is likely that the country will be able to reach this target by 2015.

These three examples illustrate Kenya’s capacity to improve care for children, and the presence of an existing infrastructure that is capable of reaching the vast majority of small children. This expected progress also indicates that the incidence of retinoblastoma is likely to rise in coming years, as more babies survive infancy and the under-five population increases.
Funding
Funding is a critical component of health systems. The government’s total health funding is 8% of total expenditure. This is a lower percentage investment than some regional countries with a lower per-capita total healthcare spend. Total health expenditure in Kenya, including government and private sources, equates to just Int$19 per person, per year. Although this is low compared to wealthier African nations, it is a higher expenditure than many countries see, and the highest expenditure of any country in East Africa.

Summary
Kenya is strategically placed at the heart of East Africa. The country has a relatively stable economy and political history, and Nairobi has developed as a financial, transport and aid centre for the region. Although troubled by ongoing corruption scandals, steps have recently been taken to clamp down on offenders.

Kenya has less of an HIV/AIDS burden than many wealthier countries, and appears to be capable of reaching major Millennium Development Goals aimed at reducing child mortality by 2015. The country has a small number of referral hospitals serving children affected by retinoblastoma, though no nationally co-ordinated care.

Located in the most densely populated rural area of Kenya, Kisumu is the country’s third largest settlement. Poverty prevents most families from accessing care in Nairobi, and the majority of Western Kenya’s children diagnosed with retinoblastoma are treated at Nyanza Provincial Hospital. This hospital also receives children from neighbouring countries due to its strategic location relatively close to Tanzanian and Ugandan borders.

Therefore, Kisumu reflects the experiences of most African children affected by retinoblastoma, and provides a good opportunity for further investigation.

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**Economic Indicators providing perspective for Kenya**

<table>
<thead>
<tr>
<th>Variable</th>
<th>Africa</th>
<th>Kenya</th>
<th>Canada</th>
<th>UK</th>
<th>USA</th>
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<td>Pop* Mid 2006</td>
<td>924M</td>
<td>32M</td>
<td>34M</td>
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<td>Pop* 2050 (Proj)</td>
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<td>Pop* Change % 2006-2050 (Proj)</td>
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<td>Urban Population %</td>
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<td>% of Pop* Living on &lt;$2 per day</td>
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<td>58</td>
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<td>% Literacy Rate M*</td>
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<td>90</td>
<td>99</td>
<td>99</td>
<td>99</td>
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<tr>
<td>% Literacy Rate F*</td>
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<td>99</td>
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<td>% Pop &lt;15*</td>
<td>42</td>
<td>43</td>
<td>18</td>
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<td>Ever Married F (16-19) %</td>
<td>23</td>
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<td>Ever Married M (16-19) %</td>
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### Health Indicators

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<th>Tanzania</th>
<th>Somalia</th>
<th>DR Congo</th>
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<td>Pop(^a) with access to good sanitation, 1999, % of Total(^b)</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>62</td>
<td>86</td>
<td>75</td>
<td>90</td>
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<td>Births per Woman(^c)</td>
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<td>5.1</td>
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<td>6.9</td>
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<tr>
<td>&lt;5 yrs Child Mortality per 1000 Children(^d)</td>
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<td>6</td>
<td>7</td>
<td>169</td>
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<td>136</td>
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<td>% &lt;5 yrs Immunised Against Polio, 2004(^e)</td>
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<td>91</td>
<td>92</td>
<td>68</td>
<td>73</td>
<td>83</td>
<td>91</td>
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<tr>
<td>% &lt;5 yrs Under Weight(^e)</td>
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<td>30</td>
<td>39</td>
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<td>% &lt;5 yrs Under Mosquito Net, 2003(^f)</td>
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<td>n/a</td>
<td>n/a</td>
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<td>15</td>
<td>7</td>
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<td>% &lt;5 yrs Under Insecticide Treated Net, 2003(^f)</td>
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<td>5</td>
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<td>Doctors per 10,000(^g)</td>
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<td>21</td>
<td>28</td>
<td>-</td>
<td>1</td>
<td>1</td>
<td>0</td>
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<tr>
<td>Nurses/Midwives per 10,000(^g)</td>
<td>74</td>
<td>54</td>
<td>97</td>
<td>-</td>
<td>9</td>
<td>1</td>
<td>4</td>
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<td>Per Capita Spent on Health (Total)(^h)</td>
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<td>$2031</td>
<td>$5274</td>
<td>-</td>
<td>$19</td>
<td>$18</td>
<td>$13</td>
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<tr>
<td>% of Total Gov't $'s Spent on Health(^h)</td>
<td>16</td>
<td>16</td>
<td>23</td>
<td>-</td>
<td>8</td>
<td>9</td>
<td>15</td>
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**Source**

Population Reference Bureau (PRB) World Population Data Sheet, 2006, except:

1 UN Social Indicators Fact-sheets, 2005
2 PRB Women of our World, 2005
3 PRB Population Health Environment Data Sheet, 2006
4 UNICEF Progress for Children, 2005
5 CIA World Fact-book, 2005
6 WHO Global Health Atlas, 2005
During our time, we visited the rural home of a child diagnosed with retinoblastoma, to learn from her family how eye cancer has impacted their lives.

Two-year-old Linda was diagnosed with unilateral retinoblastoma in July 2006, but her parents had first noticed something wrong with her eye a full year before this. On first seeing a white reflection in Linda’s eye, her parents had sought assistance from a herbalist, since they lacked the funds to pay for examination by a doctor. The couple were told this white glow was “a bad thing”, and were instructed to nightly hold their hands up before the affected eye, repeating “bad thing go away” three times. After several weeks of attempting this, Linda was taken back to the herbalist, who gave her parents herbs to place on the eye.

When the herbs also failed to work, Linda’s family began gathering together the money that would be required to pay for a doctor. However, at the local district hospital, she was misdiagnosed as having an infection, and incorrectly treated for several months. Her parents were spending precious funds on inappropriate medications.

Linda was referred to New Nyanza Provincial General Hospital (NPGH). However, she was again misdiagnosed, and treated for cellulitis for some weeks by a general doctor, before finally being referred to an ophthalmologist. This time, retinoblastoma was immediately diagnosed, and treatment began that same day.

Linda’s left eye was removed. However, NPH has just one pathologist serving the entire hospital and, as a result there are still no pathology results from the enucleated eye, six months after surgery. Enucleated eyes should always be promptly examined for signs of tumour invasion to outer layers of the eye and beyond, to ensure correct post-surgical care for high-risk patients. This may involve chemotherapy and radiotherapy.

In the absence of pathology results ruling out tumour invasion beyond the eye, Linda was treated with weekly chemotherapy, in the hope of eliminating potential extra-ocular tumour spread. However, she received a chemotherapy regimen for Burkits Lymphoma (adriamycin, vincristine, methatrexate and cyclophosphomide), a combination of drugs that are not optimal for treatment of extra-ocular retinoblastoma.

Linda’s chemotherapy drugs are provided free of charge through the generous support of a local couple, who import the drugs from India, donating them to needy children at NPH. However, these drugs are expensive, and the donors are struggling to meet demand with their own funds. This means that when Linda goes to clinic for treatment, her parents often find that only one or two of the drugs are available. Supportive drugs such as antibiotics and nutritional supplements are provided by the East Africa Children’s Fund, based in America.
On the day of our visit, Linda’s four school-age siblings were very conspicuously out-of-school. Why should this be, when primary education is now free for children in Kenya? School uniforms, books and other materials must still be purchased for students. Despite provision of free medications for Linda, the burdens for her family are great, and they can no longer afford to keep the children in school, while ensuring Linda stays in treatment.

Linda’s father earns less than US$2.50 per day, yet a round-trip bus ticket to the hospital costs US$5. There is sometimes need to stay in town during hospital stays, and extra cleaning products must be purchased to ensure Linda is protected from infection as much as possible while her immunity is compromised by chemotherapy. Sometimes there is not enough money to spare, and Linda will miss her treatment for a week.

Linda’s family are among the 44% of Kenya’s population who do not have access to good sanitation. Poor sanitation and lack of access to safe water dramatically undermines the survival of immune-compromised children receiving chemotherapy.

Like the majority of African children who lose eyes to retinoblastoma, Linda does not have a prosthetic eye. Although artificial eyes can cost as little as US$60 in Kenya, this is far more than most people can afford, and the quality is also very poor.

As a result of this lack of access to prosthetics, children frequently suffer great emotional stress. Parents may be accused of having a cursed child, and some families have even been forced out of their community by the fear and ignorance of others. The child is often actively excluded from playing with other children, or from school and wider society, Linda’s entire village came to hear about retinoblastoma.

Their response was very encouraging, especially when they saw Abby remove her own artificial eye. The community as a whole is keen to raise awareness of retinoblastoma, and work together for the future benefits that can come from Linda’s experience.
Kisumu is home to a number of hospitals, including Kisumu District Hospital, Aga Khan (Private) and the American Centre for Disease Control. New Nyanza Provincial General Hospital (NPH) was built in the 1960s with funding from Moscow, and is still referred to by locals as “Russia”. This is the only Referral Hospital for Nyanza Province, and a number of patients are also received from neighbouring countries. Frequently, more than 200 youngsters up to age 14 are admitted to the children’s ward – a unit designed to accommodate less than half that number. Many of these children wear blue trousers and t-shirts stamped with the hospital’s initials, because they have no clothing of their own. Most beds lack sheets to cover the waterproof mattresses, and the filthy, broken bathroom units have not been replaced since NPH opened over forty years ago.

The bathrooms, kitchen, sluice and storage area are currently being re-fitted, the plumbing overhauled, and the ward re-painted, thanks to a US$20,000 grant from the Griswold Foundation. American Burkitts Lymphoma researcher, Dr Rosemary Rochford, secured this funding. During this redevelopment project, the children have been accommodated in the blood transfusion unit of the neighbouring Centre for Disease Control.

Cancer Care

The most seriously ill children are treated at NPH, including children diagnosed with cancer. Retinoblastoma is the second most common cancer seen at NPH, which has a team of three ophthalmologists. These doctors lack comprehensive knowledge of the disease, but their enthusiasm and concern for the children is clear. Diagnostic tools such as X-ray and CT scan are unavailable to most families due to the expense. A neo-natal ultrasound unit is used when available, but diagnosis is routinely confirmed through biopsy, despite knowledge of its contra-indication in retinoblastoma.

NPH has no laser or cryotherapy equipment, and the ophthalmologists have no experience of effective eye-preserving therapy for retinoblastoma. Therefore, enucleation is the only curative treatment available for tumours contained within the eye, regardless of their size. With just one pathologist serving the entire hospital, post-surgical pathology is very slow, and not specific to retinoblastoma. Results following enucleation are frequently not known for several months or more.

Most children receive adjuvant chemotherapy whilst awaiting pathology results. For some, this may be unnecessary. For all, the protocol used is unlikely to be effective against extra-ocular tumour invasion. Yet more children slip into the holes created by a lack of internal communication systems. Communication between the different disciplines is unstructured and slow, with unreliable and incomplete access to fast communication tools such as email and telephone.
Children requiring chemotherapy are treated on the children’s ward. They have been allocated twenty-six beds, but frequently more than 40 children will be admitted at any given time. Consequently, many children share these beds, which are located in just two rooms of approximately 17X12ft. For immune-compromised children, infection control is an ongoing concern. Relatives are also discouraged from staying with their inpatient children, due to the lack of space to accommodate them.

There is no paediatric oncologist to direct care for these youngsters. The only resident oncologist specialises in radiotherapy, but the hospital’s ancient radiotherapy facility lies in silent disrepair. Children are referred to Nairobi for radiotherapy, but few families can afford the expense.

The hospital’s only paediatrician is in charge of care for the cancer children. Dr Julianna Otieno has no formal oncology training, but is greatly concerned about the children’s welfare and dedicated to their cause.

Only one qualified nurse is available to care for the children with cancer. Dr Rochford funds Roseline primarily as her research nurse, the only funding for an oncology nurse. Roseline trained in palliative care, but wishes to pursue training in paediatric oncology. NPH employs no auxiliary staff to support Roseline. Dr Rochford also funds a social worker, Pamela, but much of her time is consumed with basic care and housekeeping tasks, allowing little time to communicate with individual families.

Guidelines for chemotherapy are virtually non-existent. The hospital possesses a thin spiral-bound document, produced from experiences at Kenyatta National Hospital in Nairobi during the 1980s. In places, the photocopied text is illegible.

An outdated retinoblastoma protocol is summarised in less than one page. The protocol calls for carboplatin, etoposide and vincristine, but neither carboplatin nor etoposide are available. All children receive the protocol for Burkitt’s Lymphoma, (adriamycin, vincristine, methatrexate and cyclophosphomide), which is suboptimal for retinoblastoma.

No separate clinic exists for children receiving outpatient chemotherapy each Wednesday. Furniture is therefore removed from the two small rooms to a grassed area outside the ward, ensuring adequate space to accommodate children returning for treatment, as well as the inpatient children.
Chemotherapy drugs are provided without cost to the family, through the generosity of a local Indian couple, Mr and Mrs Somaia. However, costs involved are high, and many times, children receive incomplete chemotherapy treatment due to a lack of drugs.

Antibiotics and nutritional supplements are provided through the Equatorial Africa Children’s (EACH) Fund, which Dr Rochford established to improve care for children with Burkitt’s Lymphoma. Providing adequate daily meals for the cancer children is an ongoing challenge, and supplements are essential. The Dominican Friars of Kisumu also produce and donate a natural honey and aloe vera based preparation to help boost immunity during chemotherapy.

Until recently, there were no toys, educational or recreational opportunities for inpatient children. In 2005, the ABC FunShine program was launched to address this issue, and small improvements are being made through the donation of toys and dedication of several volunteers. Play is especially important for children with cancer, helping to boost their mood can have a positive impact on their response to treatment and resistance to infection.

Child Abandonment

NPH is currently facing a crisis of abandoned of treatment and abandonment of children during or following cancer treatment. Since 58% of people in Kenya survive on less than US$2 per day, many families cannot afford the transport costs of frequent hospital visits. To ensure adherence to treatment, the most impoverished children are therefore admitted. However, hospitalisation costs $2.85 per day, which the family must pay. Of course, these are often the very families who have no money, and no hope of being able to pay that bill.

Caretakers and relatives wishing to stay with children must also pay $7 per day to remain on the ward. As a result, many cannot afford to stay with their child. Some remain at the hospital gate or under nearby trees, and many times they are admitted to the hospital due to assault, malaria, typhoid, malnutrition or exhaustion. Many relatives are forced to abandon their children during treatment due to the lack of facilities and support provided for the carer.

Children are not released from hospital until their hospital bill has been paid. This creates an incentive for parents to call upon their community to ask for support. However, many families live in communities where no one has any money to spare. As a result, many children are abandoned because their relatives literally cannot afford to collect them. Many relatives fear the repercussions of their unpaid debt, and disappear completely from the area. Yet these are families who clearly love their child - most will have overcome significant obstacles to reach this hospital in the first place.
Why is awareness so vital in Africa?

There is an endemic lack of awareness about retinoblastoma in Kenya. However, this is also true of many places in the developed world. As awareness is also poor in developed countries like the UK, Canada and the USA, we must first ask what causes the difference between 97% of children surviving in developed countries, and 90% dying in Kenya.

The majority of retinoblastoma deaths in developed countries are not the result of ocular retinoblastoma, but trilateral retinoblastoma, a rare presentation involving primary mid-line brain tumours. Ocular retinoblastoma is 100% curable when it is diagnosed whilst still contained within the eye, and the vast majority of children in developed nations are diagnosed with treatable intra-ocular tumours. Most of those children with tumour invasion beyond the eye have minimal optic nerve involvement that can be treated relatively easily with post-enucleation chemotherapy, and sometimes radiotherapy. In contrast, the vast majority of children in Kenya are diagnosed with far advanced, untreated extra-ocular tumours.

The crucial difference is that parents in the developed world have generally open access to health care systems if they suspect a problem. Many of these countries also have regular child health visits and eye screening programs, at which retinoblastoma may be identified. Children can then be referred to highly experienced specialist treatment centres.
In Kenya however, there are no such systems in place, and swift access to specialist doctors is almost impossible. For example, the USA has 28 doctors per 10,000 people - among the highest ratio in the world. Kenya has just one doctor per 10,000 people.

Abundant media coverage of health topics in the developed world has created nations of highly health-aware consumers, strong individual self-advocates. In Africa, there is little access to such informed health information, beyond national basic child health awareness and campaigns against HIV, malaria and other endemic infectious diseases. Combined with the lack of money to access a doctor, such self-advocacy does not exist.

Culturally, African people do not ask doctors questions, and this is especially true among the most impoverished sections of society. Doctors, with their degrees and white coats, can be very intimidating. So awareness among parents and primary doctors in Africa is absolutely the crucial difference between a child living or dying.

Community Awareness

Approximately 80% of health care in Kenya takes place in the family home. As a result, many children with retinoblastoma die at home, without being seen by a health worker or a diagnosis. This could be reversed with access to solid knowledge, support and basic treatment.

Kibuye Parish Hall was the setting for a public awareness presentation about retinoblastoma on November 2nd 2006. This event was facilitated by local development organisation, Future In Our Hands. FIOH’s co-ordinator, Mr Rom Wandera, arranged the venue, catering, publicity, Public Address system and translators.

People gathered from across the Kisumu municipality, and several community group leaders attended from the Ugandan border town of Busia. Dr Gallie spoke about retinoblastoma, and Abby told the story of Daisy’s Eye Cancer Fund. The parents of two successfully treated children also shared their family experiences of retinoblastoma. Many questions followed these presentations. The entire proceedings were translated between English, Swahili and the local language of Luo – one sentence at a time.

On arrival, each attendee was given a copy of an awareness poster, written in Swahili. At the end of the event, all were encouraged to place their poster in a public space in their home area so that many more people could learn about this eye cancer. Everyone asked for more posters before leaving.
In all, 2,000 copies of this poster were distributed around the region and across Kenya. Nakumatt, a national supermarket chain, is also now displaying this poster in each of its stores across the country. This poster was also re-produced on t-shirts worn by members of Daisy’s Eye Cancer Fund support team.

The response to this poster campaign was dramatic. Many people wanted to help by buying t-shirts and passing on information. Requests for comprehensive information, unavailable on the poster, were frequent. Most people wished to be fully informed on all aspects of the cancer, so that they may correctly answer questions put to them at a later stage by people who have no access to the source information. We had under-estimated this response, and are very encouraged by it.

Awareness among Medical Staff

Awareness among parents is key to early diagnosis and survival. However, awareness must also be increased among medical professionals.

A large percentage of children with retinoblastoma will have been in the healthcare system for a period of time before reaching an informed physician. This delay in diagnosis is a critical failing for the individual child. Linda’s experience is a prime example. She was treated incorrectly for several months at her local hospital and at the Provincial Hospital, before being referred to an ophthalmologist.

Other children may be treated for unrelated conditions, while retinoblastoma is not identified. On October 31st, US organisation Operation Smile treated a little girl for cleft lip. Dr Gallie later observed unilateral leukocoria in the child’s photograph, during a social gathering attended by one of the Operation Smile nurses, but the child had already been released from hospital. A “white reflection in the eye” had apparently been discussed with the mother. However, as the child was clearly not in pain and apparently suffering no vision loss, the matter had not been pursued. Operation Smile is now attempting to identify the child from their own patient files.
The UK Childhood Eye Cancer Trust kindly donated 100 copies of their awareness poster, SeeRed to our mission. SeeRed targets primary doctors and paediatricians, with a text and graphic illustration of the signs they may observe whilst examining a child’s eyes. These posters were distributed across primary health centres, paediatric clinics and district hospitals in Nyanza and beyond, and more colour photocopies have been made locally to allow a further coverage. Again, the response from the staff was very positive, and SeeRed has been posted in places of maximum visibility.

Dr Gallie also gave a retinoblastoma awareness presentation at Nyanza Provincial Hospital on November 1st 2006. Doctors, nurses and other medical staff who care for children across Kisumu’s Provincial and District hospitals attended this event. Daisy’s Fund is grateful to the Dominican Friars of Kisumu, who provided a projector that enabled Dr Gallie to share her very informative Power Point presentation.

The presentation covered various aspects of retinoblastoma care, including signs, symptoms and clinical diagnosis, enucleation and the importance of post-operative pathology, and developments that may impact the care of children in developing countries like Kenya. Question-time extended for more than 90 minutes, as a raft of enthused enquiries were fired out about the diagnosis and treatment of retinoblastoma. The BBC’s World Service Western Kenya correspondent listened intently throughout the entire presentation and subsequent discussions, compiling notes for a report that was broadcast across East Africa.
Children’s cancer care in Western Kenya is currently limited and inconsistent. However, there are many reasons to be encouraged about the potential for growth and development of an effective retinoblastoma awareness and treatment program for Kisumu and the wider region of East Africa. We outline below the strengths already identified, and the areas which require further consideration and support.

Strengths Identified

- The Kenyan communities we experienced want to learn about retinoblastoma, and to share their newly acquired knowledge with others.
- The hospital staff who care for children with retinoblastoma want to improve provision for those children, and awareness in the wider community.
- Many people are dedicated to improving awareness of medical issues and saving lives, especially those of young children.
- There is encouraging local media interest in retinoblastoma.
- There is great caring for the children of Africa.

Issues Identified

**Lack of Awareness**

Diagnosis is delayed because families are not knowledgeable about childhood cancer in general. They often do not understand that children can have cancer, and specifically that cancer can occur in children’s eyes. This lack of awareness is global. However, particularly severe in Kenya is the lack a place to go for help. Health care workers at all levels are also impeded by the lack of knowledge of childhood cancer, and knowledge of retinoblastoma specifically. In their overburdened work caring for many common very serious illnesses and infections, they fail to understand that when the parents report a white pupil, it can mean life-threatening cancer in the child’s eye, or both eyes. They often also have difficulty finding a way to refer the child to cancer or eye experts.

We also must address the need for the wearer of the T-shirts, and those eager to help Daisy’s Eye Cancer Fund to have in-depth information, in order to answer the many important questions about retinoblastoma.

**Hospital Management of Retinoblastoma**

Once the child arrives in medical care, and the diagnosis of retinoblastoma is made, teams to manage retinoblastoma are not available. Ophthalmologists have difficulty focusing on retinoblastoma, communicating with colleagues and have limited experience and equipment that is common in retinoblastoma centers in other parts of the world.
The Paediatrician or Oncologist is thinly stretched with many sick children to care for, and difficulty getting drugs to treat the children. Protocols, where they exist, are old and not specific for retinoblastoma patient care. Experience is self-learned, with little mentorship. Equipment, space, beds, nurses, lab testing, diagnostic tools such as CT scan and ultrasound are scarce, and often malfunction.

Even when the diagnosis of retinoblastoma is achieved, and the primary treatment of removal of the eye may or may not have cured the retinoblastoma, the key next step of careful pathological examination of the eye is deficient. At Nyanza Provincial Hospital, one pathologist must provide service to the whole hospital: retinoblastoma eyes do not command the specific attention that the children need. If tumour is seen to have extended outside the eye, more treatment is needed to save the child’s life; if the eye was removed before tumour escaped, the child needs no more treatment.

If both eyes are affected, there is no capacity to save a less severely affected eye. The laser and freezing treatments available in developed countries do not exist. Visually useful eye must be removed to save the child’s life. Blindness is a huge challenge in Africa.

Bureaucracy may dominate over common sense. Children who have cancer and have lost an eye, or who will die of cancer, must pay bed occupancy charges before they are released to go home. Desperate families with no money see no choice but to disappear and abandon the children. The hospital ward becomes full with children who do not need to be there. All this suffering only costs the hospital more.

**Family Needs**

Even after diagnosis, teaching about retinoblastoma is not available. We found everyone was hungry for knowledge. After treatment ends the follow-up is difficult. Inadequate funds exist for the families to travel the long difficult roads to medical centers. Once at the hospital, there is inadequate accommodation nearby, and no space in the hospital for the parents to stay and care for their child. Psycho-social support is not available. Loving, kind persons do try to fill these needs when they can.

Play is important for the children at the hospital and to cope with all the challenges of retinoblastoma. No child-life support is available, which would help children undergoing procedures to understand and cooperate.

When cure is not possible, little palliative and bereavement support is available. A hospice for children with cancer is greatly needed.
Our broad long term solutions for Retinoblastoma care in Kenya cover four major goals. Beginning with Best Practice Guidelines for the care of children with this eye cancer, we also highlight the need for awareness, improved enucleation support, virtual Retinoblastoma centres and the development of patient and family supportive care systems.

**Guidelines**

Guidelines are important in the management of any medical condition, but particularly rare childhood cancers such as retinoblastoma.

Best Practice Guidelines encourage:
- Timely referral from primary health care providers;
- Optimal care for all children;
- Delivery of care at specialist centres as close to home as possible;
- Supportive care for the affected child, carers and family unit.

Guidelines already being developed in countries like the UK and Canada, could be adapted for use in Kenya.

**Awareness**

A significant reduction in mortality from retinoblastoma can only be achieved through awareness campaigns targeting the community and primary health care system.

The SeeRed poster can be:
- Adapted for more effective use in developing countries;
- Translated into Swahili (and perhaps other local languages), with cultural consideration given to the images;
- Circulated in a wider, systematic campaign among primary healthcare facilities across Kenya.

Community awareness may be greatly amplified through a piggyback campaign in conjunction with polio vaccination. Since Kenya has 73% take-up of vaccinations, and steadily increasing figures over recent years, this is likely to hold the greatest opportunity for broad targeted community awareness.
Enucleation Support

Pathology

Expert surgical review of pathology is necessary promptly after enucleation, to determine which children are at high risk for extra-ocular retinoblastoma and need prophylactic chemotherapy. Ophthalmologists could be trained to review the eyes prepared by pathology themselves. If a few become expert in retinoblastoma, they can specifically check the optic nerve and choroids. They can also have access to Internet telehealth consultations. These above measures would help reduce the risk of metastatic relapse and death in high-risk children treated with enucleation, as well as unnecessary chemotherapy treatment for low-risk children.

Communication to parents about importance of regular follow-up examinations and any instituted therapy post-enucleation.

Prosthetic eyes

Prosthetic eyes are currently of poor quality and beyond the financial means of most Kenyan people. This leads to a life-time of stigmatism and distress for the enucleated survivor of retinoblastoma.

We propose several options to make prosthetics cheaply available to such families:

1) A recycling scheme: families whose children have out-grown the eyes could donate eyes. The eyes would then be matched through a database to children in developing countries who need an eye.

2) Mass produced eyes: Plain artificial eyes could be mass-produced at low-cost. Local Kisii soap stone artists in Kenya could be trained to modify the prosthetics for individual children – since the surface of the material they already work with is very similar, they would be ideally suited to develop the necessary skills. Prosthetists would be invited to volunteer to teach these skills.
Retinoblastoma Virtual Centres

The first priority for Kenya is to save lives through increased community and primary health care awareness. Assuming these awareness campaigns are successful, and the numbers of children diagnosed at an earlier stage increases, the opportunity then arises to save eyes as well as lives.

However, a strategy must be carefully considered for the optimal treatment of these children. Retinoblastoma is a rare and complex malignant cancer, which requires specialist care at a dedicated treatment centre.

A national retinoblastoma service for Kenya (also serving East Africa) is possible in the event of successful awareness campaigns. Such a service would include:

- Medics trained in retinoblastoma, representing Ophthalmology, Oncology, Anaesthetic and Pathology
- A clinic vehicle equipped with indirect ophthalmoscope, anaesthetic, ultrasound, laser, cryotherapy and RetCam.
- Movement of this clinic vehicle to regional centres for regular care of locally pre-screened children who are unable to access the national base and its specialist focal therapies.

A single national centre with travelling satellite “virtual centres” would overcome the poverty barrier facing many families, and allow access to optimal care for all children with Retinoblastoma. This would also decrease disruption to family life, and potentially help reduce the numbers of children abandoned due to hospitalisation far from home.

Establishment of a specialist retinoblastoma centre also creates new possibilities of saving lives when cancer has advanced outside the eye, using chemotherapy and radiation in specific protocols.

Patient and Family Supportive Care

The best outcome for a child with retinoblastoma can only be achieved if supportive care for that child, the parents or caretakers and other siblings is fully considered. Systems must be put in place to ensure practical, financial, psychosocial and other needs of the family are met.

Four of the greatest challenges for families in Kenya today are:

- Lack of access to specialist care due to cost of transportation;
- Lack of accommodation near hospital and the cost of unnecessary hospitalisation for children receiving chemotherapy;
- Lack of access to detailed information about retinoblastoma;
- Lack of play space in hospital, opportunities for play and child life intervention.
Transportation
We propose the development of a travel sponsorship program, engaging airlines, private pilots and private companies, national bus companies and private taxi firms to transport children at minimal or no cost to treatment centres. This would provide the companies involved with a good image within the community, potentially increasing local and national usage (and thus revenue), whilst also overcoming the financial challenge of transportation for affected children.

Accommodation
We propose the building of a house near the hospital in Kisumu, to accommodate children requiring investigations or treatment for retinoblastoma (and any other childhood cancer).

A family house would help:
• Accommodate the child and family outside hospital, thus keeping the family together and reducing costs;
• Reduce the risk of, or prevent abandonment of both treatment and child;
• Account for the child’s whereabouts and ensure regular attendance at all hospital appointments;
• Monitor nutrition and hygiene standards;
• Protect the child from infection;
• Encourage emotional and practical support among resident families.

Not only would a house keep the family together and increase uptake and completion of treatment, it could also provide further services which are currently unavailable at the hospital due to lack of manpower and space, such as education for children and adults.

Children with cancer and their siblings could keep up-to-date with school-work with the help of on-site teachers.

A resource room and information officer could provide information about children’s cancers, plus access to extra resources for families. For example, income-generating schemes and credit union co-operatives which may help boost finances to meet the child’s special needs, and better equip the family for their return home at the end of treatment. A resource room could also be open to the wider public so that they too can learn about childhood cancer.

Such a house would support a number of the United Nations Millennium Development Goals, such as access to health care, food and education.
Retinoblastoma Information

We propose the development of an information folder for families, with fact sheets and booklets appropriate to varying stages of the child's care. This information can be available to families on request, and should also be disseminated at the relevant stages during diagnosis and treatment.

Child life Support

We propose the development of a Child life program to provide support for children and their families undergoing the challenging life events of retinoblastoma such as surgery, the loss of an eye, cancer therapies and the death of a family member.

Child life specialists are trained professionals who help children manage stressful and potentially traumatic experiences. Their work directly reduces financial burden, for example by avoiding unnecessary sedations through preparation of the child for specific procedures. Child Life specialists encourage optimal development and wellbeing, while they work in hospitals, clinics and other settings across the globe to promote effective coping through play, education, and self expression.
CONCLUSION

Children with retinoblastoma do not need to die. We know of treatments available to restore their health, but many of children will be lost in the cavernous divide between rich and poor, poverty having stripped them of their basic human right to effective health care.

A key strategy to reducing mortality from retinoblastoma is to address the factors which cause or contribute to late diagnosis and lack of access or adherence to treatment. The vast majority of children could be saved through low-tech, evidence-based, cost-effective measures. These include improved health-care seeking practices among families, access to informed health care providers and information about retinoblastoma, better integration between the systems which deliver cancer care, and the care of carers.

Measures such as improvements in sanitation, protection from infection, feeding programs, transportation and accommodation, prevention of abandonment and others must be implemented simultaneously to reduce the risks to children while in treatment. With simple significant steps, we can move forward towards a day when no child faces death from retinoblastoma.
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