‘Current Status and Future Prospects for Retinoblastoma in Ethiopia’
A meeting of health professionals, parents, and practitioners
MINUTES

Meeting held on March 29, 2014
at the Ras Amba Hotel, Addis Ababa, Ethiopia

Present:

Mulusew Asferaw (MA) (Ophthalmology, University of Gondar)
Sister Atsede (SA) (Ministry of Health, Ethiopia)
Molla Ayele (MA) (Ministry of Health, Ethiopia)
Faith Barasa (FB) (Daisy’s Eye Cancer Fund, Kenya)
Wondu Bekele (WB) (Mathiwos Wondu Ethiopian Cancer Society)
Abu Beyene (AB) (Ophthalmology, Hayat Hospital, Addis Ababa)
Ermias Kibreab (EK) (father of Bisrat)
Girma Mekonnen (GM) (Sinskey Eye Institute, Addis Ababa)
Brian Ouma (BO) (Daisy’s Eye Cancer Fund, Kenya)
Jakob Schneider (JSch) (Pathology, Black Lion Hospital, Addis Ababa)
Abiy Seifu (AS) (Faculty of Public Health, Addis Ababa University / Ethiopian Public Health Officers’ Association)
Jed Stevenson (JS) (minutes, convenor of meeting, father of Isaac)
Yemesrach Tadesse (YT) (American Academy of Refractive and Cataract Surgery)
Getahun Tsegaye (GT) (father of Abel)

Apologies:

Emebet Girma (EG) (Ophthalmology, Hawassa University)
Mekonen Tadesse (MT) (father of Edelawit)
Samson Tsegaye (ST) (father of a child with retinoblastoma)

1. Orientation

Retinoblastoma (Rb) is a cancer of the eyes that is fatal when untreated, but curable if identified and treated early. It affects children worldwide, but rates of survival vary dramatically from near 100% in the United Kingdom to probably less than 10% in Ethiopia.

The **goals** of this meeting were:

1. To strengthen networks among families and professionals concerned with Rb in Ethiopia.
2. To investigate ways of improving Rb services in Ethiopia.

2. Welcome

JS welcomed the participants and noted that those in attendance represented key **stakeholders** for retinoblastoma in Ethiopia:

- representatives from the Ministry of Health (MA and SA)
- directors of charities active on child cancer in Ethiopia (WB) and Kenya (BO and FB)
- physicians practicing in Ethiopia with specializations in Ophthalmology (AB, MA, and GM) and Pathology (JSch)
- a member of the Public Health Officers’ Association of Ethiopia (AS)
- the Ethiopia representative of the American Academy of Refractive and Cataract Surgery (YT)
- members of 3 families affected by retinoblastoma (EK, GT, JS)

Apologies were noted from EG (Hawassa University), and parents MT and ST.

3. Overview of retinoblastoma in Ethiopia

The meeting heard testimony from two ophthalmologists with extensive experience treating Rb in Ethiopia.

MA gave a presentation based on cases seen at Menelik II Hospital in Addis Ababa (the country’s highest referral centre) in the year 2007-2008. Twenty-seven cases were reported (24 unilateral and 3 bilateral), with mean age of presentation 40 months (range: 8 months - 7 years). The protocol was to refer abroad if eyes were stages A to D, to enucleate stage E eyes, and to exentrate if extraocular dissemination was suspected. Twelve cases presented with leukocoria and 13 with fungating masses; 10 cases were treated with enucleation, 10 with exentration, and 5 with chemotherapy. The chemotherapy regimens included vincristine, doxyrubicin, and cyclophosphomide. Sixteen cases were biopsy proven, of which 5 demonstrated optic nerve involvement. Follow-up was low (70% were lost to follow up), and rates of survival are unknown.

EG asked JS to tell the meeting that in Hawassa, the primary referral centre for Southern Ethiopia, caseloads are currently very high, with as many as 4 new cases per week (more than 200 per year). Only 10% of cases present with early signs (leukocoria or strabismus) and 90% are very advanced at presentation (proptosis or fungating masses).

MA emphasized that earlier detection and prompter treatment would improve children’s chances of survival and retention of sight. Multidisciplinary approaches are needed to improve management and adherence.

4. Rb diagnosis and treatment in Ethiopia: Parents’ perspectives

EK and GT described their families’ experiences of Rb treatment, recounting the journeys their children, Bisrat and Abel, have taken from diagnosis through treatment and after. They also highlighted challenges faced by families with Rb in Ethiopia in general.

Bisrat was diagnosed with bilateral Rb at age 4 months at Menelik II Hospital in Addis Ababa, after his grandparents had noted that he wasn’t following people or objects with his eyes. Enucleation of both eyes was “the only option” offered to the parents; chemotherapy was not available. Faced with opposition from relatives, the family delayed treatment while investigating alternatives. Friends connected the family to Daisy’s Eye Cancer Fund, who assisted in arranging treatment in Nairobi. At Kenyatta National Hospital, Bisrat underwent chemotherapy (vincristine-etoposide-carboplatin) as an in-patient, but the therapy was discontinued after 3 cycles because of persistent infections, and enucleation of both eyes was carried out soon afterwards. Medical bills were covered by DECFK with the assistance of the Ethiopian community in Nairobi. Now four-and-a-half years old, Bisrat is developing well.

Abel was diagnosed with unilateral Rb at age 3 months, at Menelik II Hospital. At birth a physician had noted that one of his eyes appeared smaller than the other, but consultations with other doctors did not at first yield any diagnosis; many said, ‘There is nothing wrong.’ After the diagnosis, Dr Abonesh (a paediatric ophthalmologist in private practice) connected the family with Kenyatta National Hospital in Nairobi, where the affected eye was enucleated. The family paid for travel costs; costs of treatment were covered by DECFK. Abel is now a healthy 6 year-old, but the family has had trouble obtaining well-fitting prosthetic eyes.

Regarding **challenges** for families with Rb in Ethiopia, ET drew attention to the lack of community awareness of Rb; the influence of relatives and neighbours who are often opposed to enucleation; and difficulty obtaining prosthetic eyes. GT emphasized the unreliability of chemotherapy drug supplies (some parents resort to buying chemo agents on the black market, at great expense) and the lack of awareness among health professionals -- as evidenced by the many physicians who failed to recognize Abel’s signs of Rb.

5. Combatting children’s cancer in Ethiopia: Challenges and prospects

The **Mathiwos Wondu Ethiopian Cancer Society** (MWECS) is Ethiopia’s foremost cancer NGO. Mathiwos Wondu died of leukaemia in 2001, at the age of 4, and in 2004 his father, WB, established MWECS with the aim of fighting cancer in Ethiopia. With more than 600 members and 7 employees, MWECS activities include awareness-raising, advocacy, and support projects. One of its initiatives, the Paediatric Cancer Impact Mitigation project, has supported 112 patients so far -- including 8 with Rb -- and is currently supporting 50 families by paying medical and laboratory bills, assisting with transport to and from Addis Ababa, and providing an allowance of Birr 500 (USD 25) per month for food. MWECS has coordinated a National Consultative Meeting on Non-Communicable Diseases, and, with the support of First Lady Mrs Roman Tesfaye, established the Ethiopian Cancer Control Committee.

6. Progress on retinoblastoma in Kenya: Challenges, and lessons for Ethiopia

Daisy’s Eye Cancer Fund, Kenya (DECFK) has made great progress on Rb in Kenya. Established in 2007, the first two years of the organization’s work were devoted to mapping the state of care and services in Kenya, and to meetings with key stakeholders. The result of this effort was the Kenyan National Retinoblastoma Strategy (KNRbS), developed in partnership with the Kenyan government. Achievements of the past 5 years include: standardization of treatment protocols, streamlining of the referral system, shortening of stays in hospital by beginning treatment promptly upon arrival, reduction in rates of therapy abandonment, securing chemo drug supplies, reduction of pathology processing time from 4 weeks to 2 weeks, and provision of affordable prosthetic eyes. An important part of DECFK’s approach has been the recruitment of national champions (including local doctors) and cultivation of close relationships with the Kenyan government and foreign supporters (notably physicians based in Toronto, Canada).

7. General discussion

To orient discussion, JS posed the following questions:

“Is this kind of meeting useful? Is it worth repeating (if so how frequently)? Who should be present who isn’t? What should be the most important immediate priorities or actions? If $10k or $100k were available to support work on Rb in Ethiopia, where would it be best invested?”

7.1 *Is this kind of meeting useful? Is it worth repeating? Who should be present who isn’t?*

MA voiced strong interest in meeting again, on at least an annual basis.

JS advised further mapping of services and key stakeholders using MWECS and MoH contacts, and employing tools developed for ‘service mapping’ in Kenya by DECFK.

7.2 *What should be the most important immediate priorities or actions?*

AS identified raising public awareness of Rb as a priority. The Ethiopian Public Health Officer’s Association is in a position to help with this, and has a track record of raising awareness of other health issues through its conferences and through social media. SA cited Health Extension Workers and the Health Development Army (the lowest levels of the government health workforce) as important allies in raising awareness. AB underscored the importance of improving awareness among health professionals as well as the public in general.

SA and MA suggested that the MoH might host a Technical Working Group on Rb in Ethiopia, with participation of key stakeholders.

WB advised on institutional formats for an organization devoted to Rb in Ethiopia. The most appropriate vehicle would be an institution licensed to carry out Income Generating Activity (IGA), since a charity transferring all funds directly to beneficiaries would be unsustainable. The organization should have active participation from parents in defining its mission and overseeing its work. BO approved of this approach over the alternative of setting up an Ethiopian chapter of DECF, on the grounds that a homegrown organization would be better able to devise strategies appropriate to Ethiopia. SA and WB suggested that JS should define a vision for the organization. JS agreed to draft a statement, on condition that others would criticize and revise it as necessary.

7.3 *If $10k or $100k were available to support work on Rb in Ethiopia, where would it be best invested?*

WB suggested the best investment would be in seed funds for an organization devoted to Rb in Ethiopia. Others agreed.

8. Identification of priorities for future action

Participants agreed to carry out the following actions as soon as possible:

1. Write up an account of the meeting and to distribute it to interested parties by email. **ACTION: JS** by April 6, 2014
2. GT and EK should join MWECS as “non-paying members” to formalize the relationship between the Rb parents and MWECS. **ACTION: EK, GT** April 2014
3. Distribute a form created by DECFK to key contacts at Ethiopian hospitals, for them to use in cataloguing caseloads and documenting existing services and facilities for Rb care. Representatives from Gondar, Hawassa, and other hospitals should fill out the form and return to JS. **ACTION: JS, MA, EG** May 2014
4. Draft a vision statement for a retinoblastoma organization to be established in Ethiopia. Elicit feedback from others. **ACTION: JS *et al.*** May 2014
5. Provide information to the group, by email, on procedures for legally establishing an organization dedicated to Rb in Ethiopia. **ACTION: WB** May 2014
6. Liaise with MoH regarding establishment of a Technical Working Group on retinoblastoma with representation from key stakeholders, including parents and experts in ophthalmology and oncology. **ACTION: WB, MA, SA** June 2014

Future meetings

The next meeting will be held in Addis Ababa in late 2014 / early 2015.

Summary of actions from the previous meeting, held in February, 2013:

Ref	Actions	Name	Deadline	Status
1	Share account of the meeting with interested parties	JS	March, 2013	Completed
2	Contact Wondu Bekele, director of Mathiwos Wondu Ethiopian Cancer Society, for advice	MT	February, 2014	Completed
3	Look into legal procedures for establishing an NGO in Ethiopia	GT	March, 2014	Ongoing