

## AMCC RB Workshop 14-15 March 2022, Kampala

### 1- Context and Background:

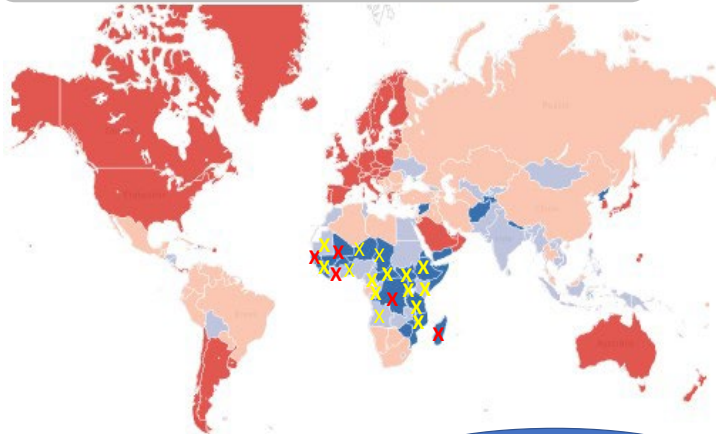
“Alliance mondiale contre le cancer” (AMCC) is an NGO committed to supporting multidisciplinary teams for the early diagnosis, access to treatments, rehabilitation and follow-up of children with retinoblastoma (RB) in sub-Saharan Africa. The first action was in Bamako (Mali) in 2011 and then in 4 other cities (Lubumbashi, DR Congo, Dakar, Senegal, Abidjan, Ivory Coast and Antananarivo, Madagascar). The demonstration of a positive result was obtained in Mali and published in 2018. Then a proposal for a new Program RB 2019-28 was elaborated at the end of 2018. The aim of this new program was to extend the support to all French and to some English and Portuguese speaking countries in sub-Saharan Africa for 10-year duration, and to contribute to the WHO goal of 60% survival rate of children with cancer in 2030.

**PROGRAM 2019-2028** Continuation of Implementation in the 5 initial countries **X** and extension to all Frenchspeaking sub-Saharan countries (280 M inhab) and some English and Portuguesespeaking ones **Y** (320 M inhab)

about 1 100 new RB cases/year

Objective at 10 years :

**70% cure rate** of expected cases



- **How ?** Thanks to Swiss Foundation and Institut Curie in Paris, by financially supporting
  - **Early diagnosis** multiyear plan in each country with ministry of health
  - **Training** (ophthalmologist, ocular prosthetist, pathologist...)
  - **Providing equipment** (Laser diode + helmet, fundus camera,...)
  - **Registration** of all cases in a common database
  - **Advocacy** to reduce the cost for parents

#### • Achievements:

- International steering committee
- Full time manager of the program (Dr Karim Assani, Kinshasa, DR Congo)
- Already deployed in 20 countries
- Living network (Meetings in Dakar, Kampala...)



Launched in June 2019

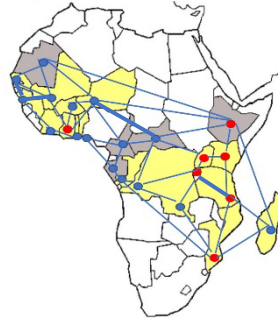
This program was built in complementarity with GFAOP (French African Group in Pediatric Oncology) for French Speaking countries and it is supported by a Swiss Familial Foundation through Curie Institute in Paris for 5 years, which has enabled the recruitment of a full time manager and helps the teams by financial supporting of early diagnosis plan, training, providing some equipment and registration of all cases, through a partnership agreement between teams, hospitals and AMCC with reciprocal commitments Regular Zoom discussions take place with the teams as well as physical multidisciplinary team meetings (a team : ophthalmologist + pediatric oncologist + pathologist + ocularist) to strengthen the network despite Covid Pandemic.

The first physical meeting was for French Speaking teams in Dakar (Senegal), 5<sup>th</sup> to 7<sup>th</sup> September 2021 with 15 teams from 12 countries and 70 attendees.



## Network between teams participating to the Program RB 2019-28

Countries having already sign a partnership agreement (in yellow) and countries on the way for signing (in grey).



### 2- Retinoblastoma Workshop in Kampala 14<sup>th</sup> and 15<sup>th</sup> March 2022:

This second workshop in Kampala was in line with the strengthening of the network between teams treating RB in English and Portuguese speaking sub-Saharan Africa. It was scheduled as a **SIOP Africa pre congress workshop** just before SIOP-Africa congress, in partnership with Uganda Cancer Institute and SIOP Africa.

#### Attendance:

102 persons were attending, ophthalmologists, ocularists, pediatric oncologists, pathologists from 15 teams (Maputo, Dar Es Salam, Kilimanjaro KCMC, Mwanza Bugando, Dodoma, Nairobi KNH, Addis Ababa Saint Paul, Addis Ababa Menelik II - Black Lion hospitals, Jimma -Ethiopia, Gondar- Ethiopia, Kabgayi – Rwanda, Accra – Ghana, Kumasi – Ghana, Tamale – Ghana, UCI, Mbarara, Uganda Ophthalmologists and Uganda Ophthalmic clinical officers) and 7 countries.

#### Aim:

The objectives of this 2 days' workshop were to share experiences of each country in early diagnosis of RB, different aspects of patients' care, data collection and research.

#### Content:

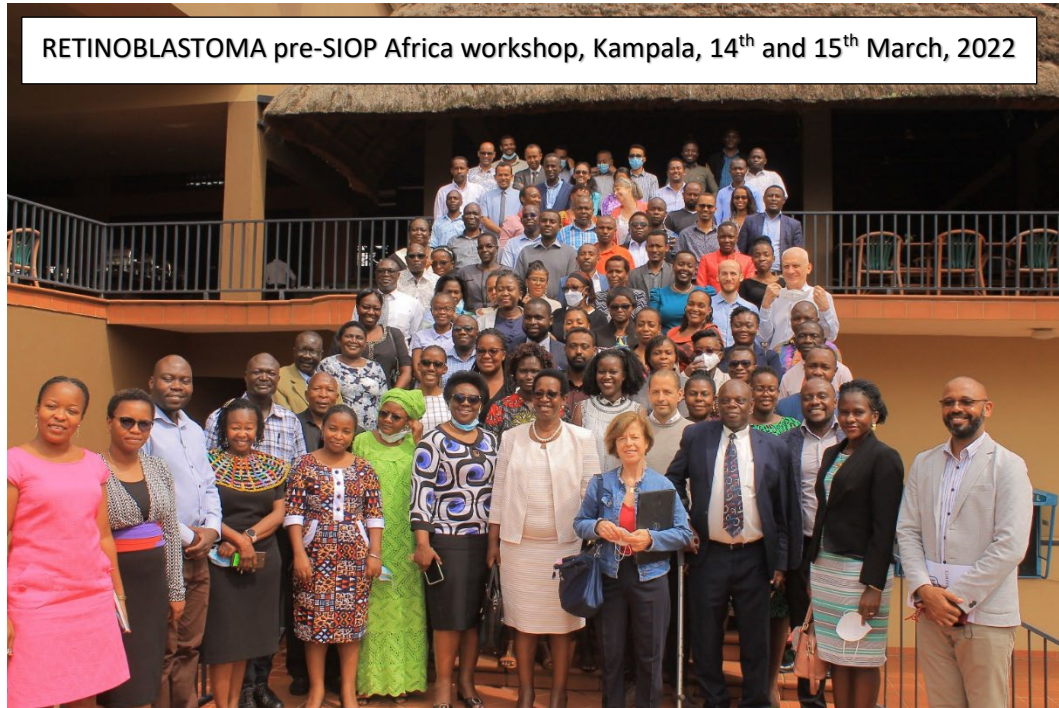
After 3 presentations by world-renowned specialists on RB (Guillermo Chantada, *Spain*, Didi Fabian, *Israel* and Laurence Desjardins, *France*), discussions were rich in plenary sessions and also in breakaway sessions by specialty with one specific day for ocularists as prosthesis is an important aspect of rehabilitation after enucleation.

**The take home messages was RB program is the program of the teams**, with a unique opportunity to be supported through the AMCC program, provided that:

- **Early diagnosis multi-year plan is written** by all the teams for the country with agreement of the ministry of health
- **All the teams develop multidisciplinary** care of children with RB and organize at least one referent center per country for conservative treatments to preserve eye and vision in bilateral cases
- **All teams collect data** on a common basis for all cases of RB in the country.

- **All teams advocate for reducing the cost** for RB care. No child should die of a curable retinoblastoma because of financial barriers.

All the teams are invited to participate to the regular webinar every 2 weeks to discuss together difficult cases.



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