SOCIÉTÉ INTERNATIONALE D'ONCOLOGIE PÉDIATRIQUE

SIOP

Curing paediatric cancer in Africa

SIOP Africa newsletter

International Society of Paediatric Oncology

July 2020

SIOP Africa 21 meeting in UGANDA postponed

Dear SIOP Africa members

The SIOP Africa Board of Directors has been following closely the situation of the COVID-19 pandemic in Africa and its impact on health systems and childhood cancer care.

In consideration of current travel restrictions and social distancing concerns related to COVID-19, The SIOP Africa Board would like to inform the PO community that the biannual SIOP Africa meeting cannot be held in Uganda on January 2021. We are exploring options for offering some lectures in a virtual format and postponing the Uganda meeting to end of 2021 – beginning 2022. After reviewing the best options, the Board will make a final decision as soon as possible in order to allow members to plan accordingly.

SIOP Africa remains committed to improve pediatric cancer care in Africa and adapting her strategy according to the challenges that the African pediatric oncology teams are facing currently.

Laila Hessissen
SIOP Africa President

Joyce Balagadde Kambugu
SIOP Africa President Elect

African Paediatric Oncology in times of COVID – 19 pandemic

The COVID-19 pandemic was confirmed to have spread to Africa on 14 February 2020. The first confirmed case in Africa was in Egypt, and in sub-Saharan Africa Nigeria. Most of the identified imported cases arrived from Europe and the United States rather than China where the virus originated. It is believed that there is widespread under-reporting in many African countries with less developed healthcare systems.

Experts worried about COVID-19 spreading to Africa, because many of the healthcare systems on the continent are inadequate, having problems such as lack of equipment, lack of funding, insufficient training of healthcare workers, and inefficient data transmission. It was feared that the pandemic wouldbe difficult to keep under control in Africa, and cause huge economic problems if it spread widely.

On 12 July 2020, WHO reported 458, 329 cumulative cases in Africa (excludes Morocco and Egypt) and 8 049 deaths in 47 countries most of the cases have been reported in South Africa, Nigeria, Ghana and Algeria.

Coronavirus infection in children represents about 10% of the reported cases but the pandemic is now affecting children and families far beyond those it directly infects. Schools are closing, family incomes are being lost. Parents are struggling to care for their children and make ends meet.Although children do not represent a high-risk group for direct COVID-19 fatality, the pandemic poses far-reaching secondary impact that heightens risks to African children's rights and wellbeing:

• The rapid spread of COVID-19 is overburdening the under-resourced African health systems and disrupting routine health services.

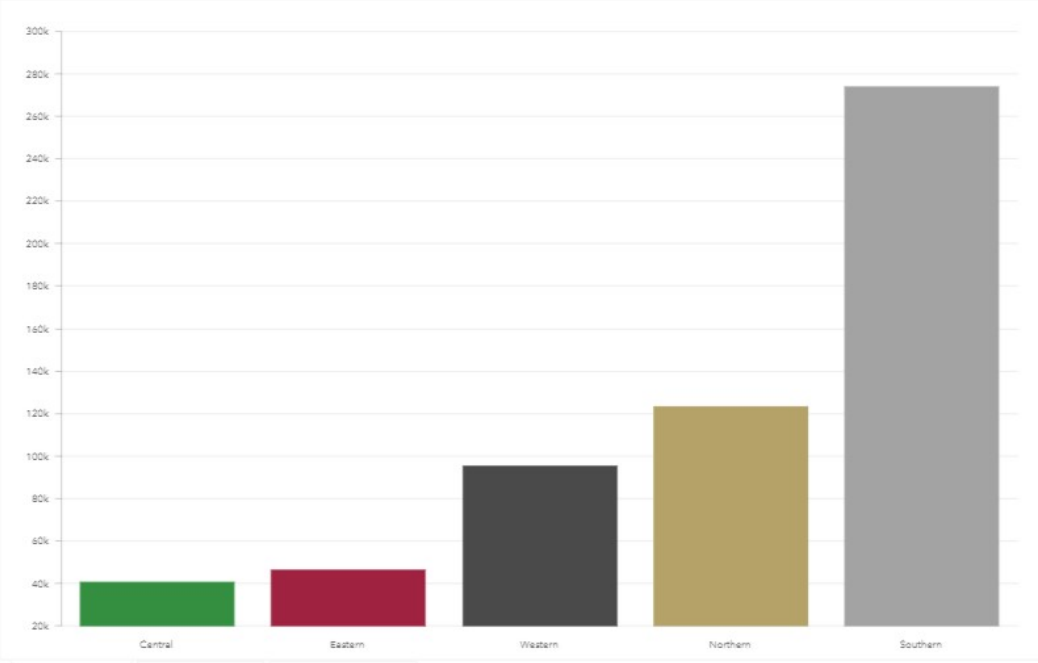
• The COVID-19 pandemic is compromising Africa's children formal learning, health and safety/protection, particularly the girls.

• COVID-19 pandemic is unfolding in Africa against a backdrop of worrying hunger levels driven by climate shocks, conflict and economic challenges.

• COVID-19 pandemic is exacerbating existing vulnerabilities. This pandemic also has a catastrophic impact for the most vulnerable who do not have access to social protection system, including the most vulnerable children.

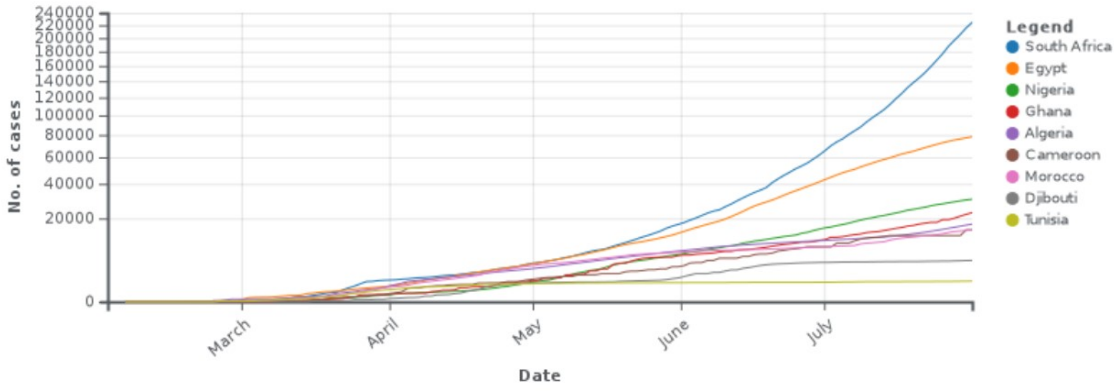
• COVID-19 pandemic threatens to reverse development progress in Africa.

Cases by region (updated on 11 July 2020)



Total confirmed cases by country [edit]

Daily cases for the most infected African countries:

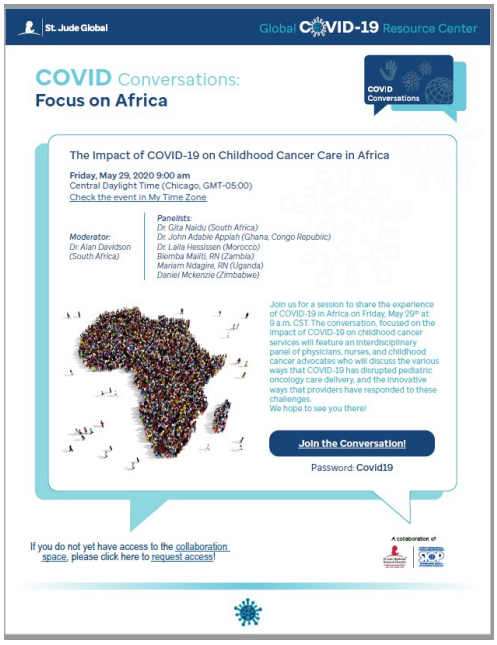


Among vulnerable children, pediatric oncology patients in Africa have been impacted by the COVID – 19 pandemic. Few cases of coronavirus infection have been reported in African pediatric oncology facilities, but even in the early epidemiological phase, when health-care systems had not yet been substantially affected, COVID-19 affected the care of children with cancer.

To evaluate the situation and the impact of the COVID – 19 pandemic on the management of children with cancer in Francophone Africa, the Francophone African paediatric oncology GFAOP conducted a survey from May 1-15, 2020, evaluated the impact of the COVID-19 pandemic on childhood cancer management in the Francophone African paediatric oncology facilities. Twenty-five centers across 15 countries completed the survey. At the closing date of the investigation, no cases of COVID – 19 were reported in paediatric oncology settings. Protective supplies and equipment provided by hospitals were considered to be insufficient in 80% of the centers. Only 35% of the centers had adapted their work spaces. The overall activity level in paediatric oncology was reduced in the majority of centers (60%). The impact of the COVID-19 pandemic on childhood cancer treatment in the centers was mild (61%) to severe (24%). Forty-six percent of centers had a deficit in blood for transfusion. Fifty-four percent of centers considered that COVID-19 had a negative impact on the management of the six priority paediatric cancers of the WHO Global Initiative for Childhood Cancer. The centers' adaptations were mainly wide use of telephone to manage patients by (33%), and reinforcement of hygiene and distance measures (20%).

It is obvious that the COVID-19 pandemic will have a negative impact on the overall survival of children with cancer. This impact is much more an indirect impact and the International Society of Pediatric Oncology is participating inminimizing the effect of the Pandemic. Through the SIOP Africa network, SIOP empowers the local paediatric oncology teams and enhances their resilience skills by allowing them to benefit from shared experiences and information.

COVID conversations



The Global COVID-19 Observatory and Resource Center launched the COVID Conversations, a live webinar to discuss difficult issues, address pressing questions, and hear the experiences of our colleagues when it comes to caring for children with cancer during this pandemic.

A first webinar about Paediatric oncology in French speaking Africa during COVID 19 pandemicwas held on Tuesday May 19$^{th.}$ This webinar was organized by the St Jude Children Research Hospital in partnership with the SFCE Société Française des Cancers de L'Enfant and the Groupe Franco-Africain d'Oncologie Pédiatrique GFAOP. During this conversation the panellists reported the experience of COVID in paediatric oncology patients in France and the ways that providers from Francophone Africa have responded to the challenges faced during COVID outbreak.

The conversation of COVID-19 in Africa was organized on Friday, May 29th and focused on the impact of COVID-19 on childhood cancer services. The session included an interdisciplinary panel of physicians, nurses, and childhood cancer advocates who discussed the various ways that COVID-19 has disrupted pediatric oncology care delivery, and the innovative ways that providers have responded to these challenges.

The Cancer Access Partnership

Cancer Access Partnership is expected to result in a 59 percent savings on procured cancer medicines

The American Cancer Society (ACS) and the Clinton Health Access Initiative (CHAI) today announced agreements with pharmaceutical companies Pfizer, Novartis, and Mylan to expand access to 20 lifesaving cancer treatments in 26 countries in sub-Saharan Africa and Asia. Purchasers are expected to save an average of 59 percent for medicines procured through the agreements.

Medications included in the agreements cover recommended regimens for 27 types of cancer and enable complete chemotherapy regimens for the three cancers that cause the most deaths in Africa—breast, cervical, and prostate. These cancers are highly treatable and account for 38 percent of cancers in the countries covered in the agreements. The new agreements include both chemotherapies and endocrine therapies aligned to evidence-based guidelines harmonized for sub-Saharan Africa, and expand access to additional formulations, including those essential for treating childhood cancer.

Sub-Saharan Africa's cancer burden is significant and growing. In 2018, there were an estimated 811,000 new cases of cancer and 534,000 deaths from cancer in the region. Cancer patients in sub-Saharan Africa are twice as likely to die as those in the United States, often due to late diagnosis and lack of access to treatment. Based on population aging alone, annual cancer deaths in sub-Saharan Africa are projected to almost double by 2030. The new agreements reach 23 countries in Africa, covering 74 percent of the annual cancer cases.

The new initiative includes Pfizer, Novartis, and Mylan, and will expand access to the priority medications and formulations in the agreements to additional countries. All of the medications included in the agreements meet the quality standards set by a stringent regulatory authority such as the U.S. Food and Drug Administration (FDA) or the European Medicines Agency (EMA). These medicines will be available for purchase at newly and independently negotiated prices in the designated countries and the companies have committed to monitoring the impact of their respective agreements with CHAI.

The Clinton Health Access Initiative (CHAI) in partnership with the American Cancer Society (ACS) launched the Cancer Access Partnership with Novartis and Mylan last month. This is an expansion of their previous work with Pfizer and Cipla which you can read more about here.

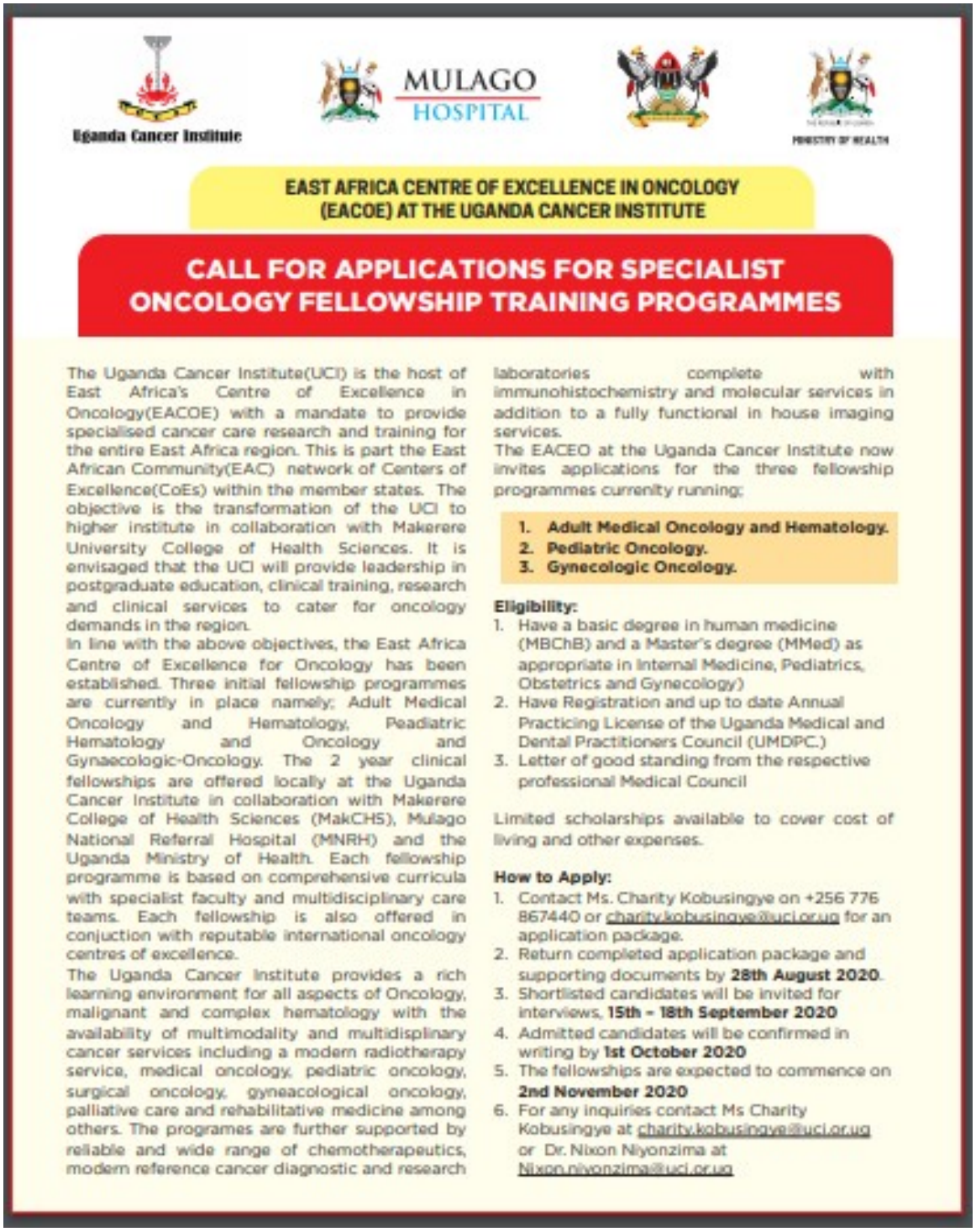
This partnership provides a range of twenty anti-cancer medicines in twenty-nine different formulations, including thirteen pediatric formulations indicated on the WHO Model List of Essential Medicines for Children, in 23 countries in sub-Saharan Africa. These countries make up 78% of cases 0-14 years old in the region. Compared to the 2017 agreements, the partnership has expanded to include some key additions for pediatric cancer treatment such as daunorubicin, cyclophosphamide, filgrastim, and methotrexate tablets. In addition, based on SIOP adapted regimens, the product portfolio now provides one to three medicines for a total of nine pediatric cancers including for the first time, the addition of medicines for the management of Burkitt's Lymphoma, one of the highest incidence pediatric cancers in sub-Saharan Africa.

Countries will save on average 59% on medicines procured through this agreement, enabling them to treat more patients with the same resources and facilitating patients paying out of pocket to complete their treatment cycles. All the medicines included in the partnership are approved by a stringent regulatory authority such as the U.S. Food and Drug Administration and the European Medicines Agency. More information about the partnership can be found here. If you have any questions, please reach out to CHAI and ACS via the link at this website.

Contact: Vivienne Mulema Clinton Health Access Initiative (CHAI)
vmulema@clintonhealthaccess.org

Call for applications for specialist oncology fellowship programmes

The East Africa Centre of Excellence for Oncology at the Uganda Cancer Institute welcomes all paediatricians looking to subspecialise in paediatric oncology.



Uganda Cancer Institute

MULAGO HOSPITAL

MINISTRY OF HEALTH

EAST AFRICA CENTRE OF EXCELLENCE IN ONCOLOGY (EACOE) AT THE UGANDA CANCER INSTITUTE

CALL FOR APPLICATIONS FOR SPECIALIST ONCOLOGY FELLOWSHIP TRAINING PROGRAMMES

The Uganda Cancer Institute(UCI) is the host of East Africa's Centre of Excellence in Oncology(EACOE) with a mandate to provide specialised cancer care research and training for the entire East Africa region. This is part the East African Community(EAC) network of Centers of Excellence(CoEs) within the member states. The objective is the transformation of the UCI to higher institute in collaboration with Makerere University College of Health Sciences. It is envisaged that the UCI will provide leadership in postgraduate education, clinical training, research and clinical services to cater for oncology demands in the region.

In line with the above objectives, the East Africa Centre of Excellence for Oncology has been established. Three initial fellowship programmes are currently in place namely; Adult Medical Oncology and Hematology, Peadiatric Hematology and Oncology and Gynaecologic-Oncology. The 2 year clinical fellowships are offered locally at the Uganda Cancer Institute in collaboration with Makerere College of Health Sciences (MakCHS), Mulago National Referral Hospital (MNRH) and the Uganda Ministry of Health. Each fellowship programme is based on comprehensive curricula with specialist faculty and multidisciplinary care teams. Each fellowship is also offered in conjuction with reputable international oncology centres of excellence.

The Uganda Cancer Institute provides a rich learning environment for all aspects of Oncology, malignant and complex hematology with the availability of multimodality and multidisplinary cancer services including a modern radiotherapy service, medical oncology, pediatric oncology, surgical oncology, gyneacological oncology, palliative care and rehabilitative medicine among others. The programes are further supported by reliable and wide range of chemotherapeutics, modern reference cancer diagnostic and research laboratories complete with immunohistochemistry and molecular services in addition to a fully functional in house imaging services.

The EACEO at the Uganda Cancer Institute now invites applications for the three fellowship programmes currenlty running;

1. **Adult Medical Oncology and Hematology.**
2. **Pediatric Oncology.**
3. **Gynecologic Oncology.**

Eligibility:

1. Have a basic degree in human medicine (MBChB) and a Master's degree (MMed) as appropriate in Internal Medicine, Pediatrics, Obstetrics and Gynecology)
2. Have Registration and up to date Annual Practicing License of the Uganda Medical and Dental Practitioners Council (UMDPC.)
3. Letter of good standing from the respective professional Medical Council

Limited scholarships available to cover cost of living and other expenses.

How to Apply:

1. Contact Ms. Charity Kobusingye on +256 776 867440 or charity.kobusingye@uci.or.ug for an application package.
2. Return completed application package and supporting documents by **28th August 2020**.
3. Shortlisted candidates will be invited for interviews, **15th – 18th September 2020**
4. Admitted candidates will be confirmed in writing by **1st October 2020**
5. The fellowships are expected to commence on **2nd November 2020**
6. For any inquiries contact Ms Charity Kobusingye at charity.kobusingye@uci.or.ug or Dr. Nixon Niyonzima at Nixon.niyonzima@uci.or.ug

Retinoblastoma awareness video

Retinoblastoma is the most common cancer of the eye and affects babies most often before the age of 2 years. In sub-Saharan Africa, more than 1,000 new cases are detected each year. Many of these children die because the diagnosis is often late. Yet there is a hospital in every country where these children can be cured with simple treatments at an acceptable cost. Awareness and early diagnosis campaigns are crucial.

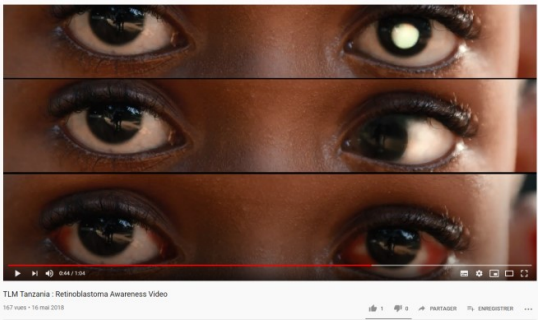
Recently two NGOs posted two awareness videos on YouTube, one in French and the other in English:

Tumaini La Maisha

CARING FOR CHILDREN WITH CANCER IN TANZANIA

ALLIANCE MONDIALE CONTRE LE CANCER

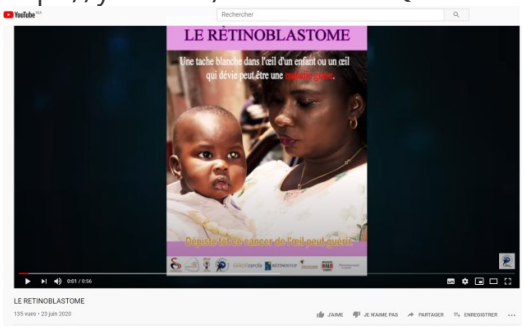
Retinoblastoma is one of the most common childhood cancers in Tanzania. This video shows some of the warning signs to look out for to save the sight and potentially the life of your child.



https://youtu.be/BM7aPyZp298

Le rétinoblastome est le cancer de l'œil le plus fréquent de l'enfant et touche les bébés le plus souvent avant 2 ans. En Afrique sub-saharienne, plus de 1000 nouveaux cas sont détectés chaque année. Beaucoup de ces enfants meurent car le diagnostic est souvent tardif. Pourtant, il y a dans chaque pays un hôpital où ces enfants peuvent guérir avec des traitements simples et à un coût acceptable.

https://youtu.be/LMHAo7TT2Qw



Global COVID-19 Resource Center

The Global COVID-19 Observatory and Resource Center for Childhood Cancer is for health care professionals focused on pediatric cancer. The resource provides a way for providers to collaborate, connect and find the latest information on COVID-19 as it relates to childhood cancer.

Health care professionals can access a collection of current resources and a pediatric cancer registry with real-time results.

If you are a patient or family member of someone with childhood cancer, you can find COVID-19-related resources on Together.

https://together.stjude.org/en-us/care-support/covid-19-resources.html

Collaborators

A collaboration of St. Jude Children's Research Hospital and SIOP.

St. Jude Children's Research Hospital
Finding cures. Saving children.
ALSAC • DANNY THOMAS, FOUNDER

SOCIÉTÉ INTERNATIONALE D'ONCOLOGIE PÉDIATRIQUE
SIOP
INTERNATIONAL SOCIETY OF PAEDIATRIC ONCOLOGY

More Information about Coronavirus and COVID-19

- The Global COVID-19 Observatory and Resource Center for Childhood Cancer | St. Jude Global (for health care professionals)

SIOP Africa Board

We are pleased to inform you that DrJoyce Balagadde Kambugu is the new SIOP AFRICA president elect. Dr. Joyce Balagadde Kambugu is a leading peadiatric oncologist in East and Central Africa with more than 10 years' experience in this field. She is based at Uganda Cancer Institute (UCI), the national referral cancer treatment, research and training center in Uganda where she directs the peadiatric oncology service.

She did her basic and graduate (Paediatrics and Child Health) training at Makerere University in Uganda; and fellowship training in peadiatric oncology at the University of Cape Town (Red Cross War Memorial Children's hospital).

While at the UCI Joyce spear headed the establishment of a dedicated paediatric oncology service and later a fellowship program in paediatric oncology. She is now engaged in extending paediatric cancer services to regional hospitals in the country and modification of the National Cancer Control Plan. Joyce is a passionate advocate for paediatric cancer in developing countries.www.siop-online.org/sp_cb/africa/

SIOP Africa membership

Members of SIOP Africa can enjoy the following benefits:

1. To be a member of a continental pediatric oncology network
2. Access to information and opportunities in the field (publications, training opportunities, meetings, scholarships .)
3. Sharing experience with African and international pediatric oncologists
4. Reduced registration fees at continental SIOP meetings in Africa

SIOP Africa members commit to being an active member:

1. Participate whenever possible in SIOP Africa activities (General Assembly, continental meetings etc)
2. Keep SIOP Africa informed of activities related to pediatric oncology taking place in their country
3. Advocate for pediatric oncology nationally, continentally and internationally
4. Exchange useful information with members of the African Paediatric Oncology community (clinical cases, publications.etc)

No fee will be charged for your membership of SIOP Africa *

You can file the form below and formalize your "SIOP Africa" membership. If you are already a member, kindly invite non-members to register.

Please send this form by Email to: Africa@siop-online.org

SIOP Africa membership form

Are you already a member of SIOP Africa?	Yes	No
If so, would you like to stay?	Yes	No
If no, do you want to become a member?	Yes	No

If you are already a member of SIOP Africa or wish to become one, please provide the following information:

Photo	insert photo JPEG
Surname (Familyname)	
First Name(s)	
DOB	
City	
Country	
Title/ specialty	
Affiliation (work place)	
Email	
Phone number (include country code)	
Field of interest **	

* The members of SIOP Africa are not necessarily members of SIOP International and vice versa

** Can you specify if you are an active member in a particular field of pediatric oncology or member of a group or other learned society (PODC, National Society of Oncology or other complementary discipline, GFAOP,CCI (parents group), other)

As a member or future member of SIOP Africa I pledge to work for the development of pediatric oncology and the respect of the statutes governing SIOP Africa.

Date: ……/……/……

Signed …….

Please send this form by Email to: Africa@siop-online.org

International Society of Paediatric Oncology SIOP news

2020 SIOP Congress to Take Place Virtually (Oct 14-17, 2020)

In light of the continuing uncertainty about the evolution of the COVID-19 pandemic and its impact on travel restrictions and physical distancing requirements throughout 2020, the SIOP Board of Directors has decided to hold the 2020 Congress as an entirely virtual meeting (October 14-17). The planned Scientific Programme will be maintained with some modification to accommodate the change in format. Most keynote speaker, symposia and meet the expert sessions will continue as originally planned. Most speakers will be present in real time, thus allowing participants to ask questions. SIOP meeting attendees will have the opportunity to present their research through oral and poster presentations and to hear the latest updates. The abstract reviews are underway and SIOP is confident that we will offer a strong scientific programme, including many interactive ways for learning, sharing, networking and interacting with our sponsors.

As part of the 2020 Congress, the Education Day, Young Investigator Day, PODC Sessions, and the sessions conducted by Nursing, Pediatric Psycho-oncology (PPO), the Pediatric Surgeons (IPSO), and the Pediatric Radiotherapists (PROS) will also be conducted virtually with slight modifications. In addition, SIOP plans to conduct virtually the Industry Sponsored Symposia, the Exhibition and the Annual General Meeting (AGM), as originally planned.

As SIOP's mission continues to focus on the global advancement of children with cancer and their families, our interest in the health and well-being of our members, many of whom are front-line providers, cannot be overstated.
We invite SIOP Africa members to register www.siop-congress.org/register

The new PODC Nurses Newsletter

Please take the time to read the inspiring stories and experiences of your pediatric oncology nursing colleagues from around the world, collected during May of 2020.
https://siop-online.org/wp-content/uploads/2020/06/Making-Global-Connections-COVID-19_June-2020_SIOP-PODC-Nursing_FINAL-3-1.pdf

in their words: stories from the bedside

TEARS OF COVID 19: Experience at Uganda Cancer Institute in-patient

KEMIGISHA MISK, Uganda Cancer Institute

What began as a story from China Wuhan ends up a reality in Uganda.

All started as rumors about a strange disease killing people in China. I did not pay much attention to it since it was a distant nation from mine. As a pediatric ward and institute at large, we were caught off guard.

I remember, the president announced closure of public transport system by 10 pm yet it was 9pm and I was still on evening duty. It struck me hard because I use public transport. I had very ill patients so could not leave ward since night staff had not reported. I had to sleep on the ward overnight, though unplanned.

By God's grace, I managed to get transport to home the following day. Administration was puzzled as only staff with personal vehicles could report for duty. Wards were left with skeleton staff: one person per 12-hour shift. A three shift duty was scaled down to two shifts. Staff, patients and caretakers all had no ideas of what was to befall them.

The first two weeks after lock down were the most difficult times, everyone panicking to see family safety. Some staff were laid off, only essential staff were allowed to continue with duties but still with few numbers. Ward workload tripled, one nurse taking on duties of three nurses and doctor's duties since they also faced similar challenges of transport. This went on for two months from March to May.

Districts all over the country put up transport system for patients so this saw wards flooding with patients. The hospital provided meals to patients, but cooks had no transport. Receiving a meal became a guess. Remember, food markets had also closed. I remember one day, I shed tears after realizing children had gone hungry for two days without meals. Yet they were on strong chemotherapy regimen. All looked exhausted; I equally could not help since I had only Ug.1000 for my breakfast.

We have experienced many challenges like ward filled beyond capacity, delays to reach hospital, shortage in supplies like blood products, reduced number of staff, to mention but a few.

Patients and attendants were encouraged to observe safety measures like handwashing, wearing facemasks, social distancing. As the saying goes, "old habits never die", few or none of these people adhered to medical advice. When interacting with some of them, they told me that they had surrendered their lives to God to decide on their fate. They were more worried about hunger killing them before the coronavirus. Sometimes I would personally forget to put on a mask. I would remember when almost finishing ward rounds.

I remember one caretaker telling me "God designed me with a huge nose and wide nostril to consume as much air as I can. Why should I distort God's design?" exclaimed the caretaker. With exception of hand sanitizing, other measures have not been fully adhered to.

As time went on, with the support of the hospital, we got used to the new system and stress levels came down. As a unit we kept readjusting to fit into the new system brought about by the pandemic. I hope with time, we shall resume our normal life.

in their words: stories from the bedside

Delivering pediatric oncology nursing care despite Covid-19: Experience

NDAGIRE MARIAM, Uganda Cancer Institute

I first heard about Covid 19 in December last year. I never thought it would reach my country. Little did I know that life as we knew it was about to change.

The first coronavirus patient in Uganda was diagnosed towards the end of March 2020. This saw the government take drastic measures to try and mitigate its spread. This saw the closure of public transport and later private cars, and putting in place a partial lock down with curfew. The question in my mind and my colleagues was "how were our patients supposed to reach hospital'. How were we supposed to reach the hospital? This put most of us in a state of uncertainty. Yes, health workers were allowed to continue going to their work places, but how were we supposed to get there? Thank God the Uganda Cancer Institute administration quickly responded by putting in place a hospital shuttle system.

The first two weeks was the hardest, this saw a reduction in our patient numbers in the OPD, missed appointments, late coming of both staff and patients, and a complete disruption of the work schedule. I remember we asked a patient why he was arriving after 4pm for a regular visit, and the parent informed us that he had been riding a bicycle since 5am in the morning just to bring in his son for chemotherapy. This broke my heart. Both father and son were so exhausted. I remember a mother who had to carry her child on her back, and walk for more than 3 hours just bring in her girl for chemotherapy, yet she had to walk back and be home before the 7pm curfew. Or another 14-year-old girl who has to also walk to and from the hospital just to get her treatment.

Later patients started coming again in big numbers, but with luggage and bedding because they didn't have the means to get back home. This saw the ward and hostels getting crowded. We could not chase them away. Yet again the hospital responded by offering to transport them back home.

Children do not understand social distancing, they don't understand why their favorite nurse doesn't want to hug them today. Or why they can't get a high five from you for being brave. You fear to contract the virus. But you also don't want to disappoint your little patients.

I have had to live in constant fear of contacting the virus and perhaps infect my family. My 4-year-old boy who always gives me hugs when I get home now instead just says "mummy is from hospital, she is dirty, we can't hug her". It not easy being the only person leaving home to go to work during a lock down, you feel your neighbors are looking at you weirdly, worried you might bring the virus to the neighborhood.

Covid 19 has also taught us a lot. We have learnt to be more flexible, multi-tasking, to think "outside the books", we have adapted to a new system of working. I believe we are now a stronger team.

We have had to up our game on health education of our patients and parents especially on hand washing and use of masks.

I thank God we don't have any cases of cancer patients with coronavirus.

The journey ahead is still long and uncertain, a lot needs to be done. But am confident the lessons learnt from this era will go a long way to influence the face of pediatric oncology nursing in Uganda.

Mariam Ndagire RN, BScN PGD
Senior Nursing Officer
Pediatric Department
Uganda Cancer Institute