

2019

25th anniversary
Childhood
Cancer
International



ANNUAL REPORT

TABLE OF CONTENTS

Message From The President	2
2019 Congress	5
Board of Trustees	7
2019 Membership	8
Regional Reports	
Africa	9
Oceania	18
Europe	19
Latam	25
Asia	30
N. America	36
Closing	42

FROM THE PRESIDENT

In 2019...

Childhood Cancer International (CCI) celebrated its 25th anniversary and its mission of advancing cure and transforming care for children and adolescents with cancer and their families. We continued to build on our goals to: a/ **Establish and Strengthen Parent Groups**; b/ **Nurture Partnerships**; 3/ **Drive Global Advocacy**; and, 4/ **Intensify Awareness & Mobilize Support** for childhood cancer. Governed by the Board of Trustees with representation from North America, South America, Europe, Africa, Asia and Oceania, in addition to our 167 member organizations from 90 countries, we are the largest grassroots childhood cancer organization in the world. Together, our voices are strengthened as we advocate to leadership around the world to ensure childhood cancer is a local, national and global child health priority.



This year, CCI successfully reached key strategic goals previously set in 2012 and 2015, to make childhood cancer an integral part of the global child health agenda. To achieve these goals, CCI began advocating for the unique needs of children with cancer at the United Nation's General Assembly High-Level Meeting in 2011. In May 2015, during the 68th World Health Assembly, CCI successfully advocated for the inclusion of the first side-event focused on the global needs of children with cancer. In 2017, we successfully advocated for inclusion of language related to child and adolescent cancer and survivors of childhood cancer in the World Health Organization (WHO) Resolution: Cancer Prevention and Control in the Context of an Integrated Approach. In 2017, we submitted and received approval of our 3-year work plan required for the WHO Non-State Actor Relationship, gaining the coveted NSAR status in January 2018. In September 2018, CCI was invited as guest speaker and key partner at the launch of the WHO's Global Initiative for Childhood Cancer (GICC), held at the United Nations General Assembly, New York City. The GICC elevates childhood cancer as a child health priority with the aim of increasing global childhood cancer survival rates to 60% by 2030, thereby saving an additional 1 million children's lives, while alleviating cancer-related suffering.

During 2019—our second year as a non-state actor in official relations with the World Health Organization—we continued to expand nutritional support, psychosocial support services, palliative care and advocacy as part of our 3-year collaborative work plan in target countries including Ethiopia, Myanmar and Fiji. We distributed the WHO's Guide for Integrating Palliative Care and Symptom Relief into Paediatrics to CCI Members attending the CCI Congress in Lyon, France, as well as at regional conferences. We provided salary support for a full-time nutritionist at Yangon Children's Hospital's hematology-oncology unit and nutritional support at Black Lion's Children's Hospital in Addis Ababa, Ethiopia. We collected existing Nutrition Guides from members for development of a WHO approved parent guide for distribution in LMICs. We also expanded our reach through participation with the WHO at in-country workshops in Peru, Philippines, and Uzbekistan.

In addition to our work focused on our 3-year plan, CCI had representation on all **five Working Groups** and Subgroups of the newly created WHO Global Initiative for Childhood Cancer (GICC) throughout 2019 participating in the development of key messages and key activities.

These included working groups focused on 1/ **Policies**; 2/ **Access to Medicines and Technologies**; 3/ **Quality Centers (Service Delivery, supportive care)**; 4/ **Registries, Costing & Research**; as well as, 5/ **Advocacy**.

On February 15th—International Childhood Cancer Day—CCI launched the second year of a 3-year social media campaign called **#nomore**. The year’s key messages focused on: **#nomorepain** and **#nomoreloss**. Assets were circulated online and to members attending the Annual General Assembly in Kyoto (November, 2018), in time for translation and preparation for a successful 2019 ICCD global awareness campaign. Together, we highlighted the enormous need to abolish disparity of the global survival rate of childhood cancer, while eliminating the associated pain and suffering of cancer treatments.

A young girl with a joyful expression is sitting on the floor, leaning her head on her hand. She is wearing a pink and white plaid shirt. In front of her is a large, light brown teddy bear. The background is a plain, light color.

Join us in saying...

No more loss.

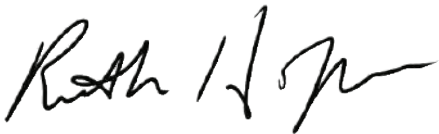
In collaboration with the World Health Organization, our goal is to bring the global survival rate of childhood cancer up to 60% by 2030.

In 2019, as the global voice of the parents and families of children with cancer, CCI continued to build relationships and expand our global partnerships. In addition to our ongoing alliances with SIOP, UICC, NCD Child, ICPCN (International Children’s Palliative Care Network), the Maruzza Foundation and St. Jude Children’s Research Hospital, CCI was thrilled to announce our new partnership with La Roche Posay Foundation in February at a global press conference in Paris, France. Working with the LRPF team, CCI board members and regional representatives, were thrilled to launch a collaborative website to provide support to families of children with cancer, in addition to developing a therapeutic massage toolkit which parents could use to reduce anxiety during their children’s cancer treatments. ACCO looks towards 2020 and the expansion of these programs to more countries, while continuing to build upon all of CCI’s partnerships.

CCI's achievements over the past 25 years are remarkable! CCI is now a recognized and respected global network, championing and unifying the voices of parents and families of children and adolescent cancer patients and survivors. We are the preferred partner of International Development Organizations.

As we look towards our next 25 years, we look forward to building an even more robust network by increasing interactions of members, expanding and sharing our knowledge and experiences, and preserving the spirit on which we were founded - We Care, We Share.

I am so grateful to each and every one of you - for your work, your passion, your compassion, your dedication, your innovation, your vision... because more than 400,000 children will develop cancer in 2020 and no child or family should ever fight cancer alone.



Ruth I Hoffman, MPH

President, Childhood Cancer International



2019 CONGRESS

In October, 160 parents, survivors and patient representatives of 42 countries from around the world came together in Lyon to celebrate our 25th anniversary, and to share and learn from each other at CCI's International Congress and Annual General Assembly (AGA). We were grateful for the hospitality and generosity of our host and Local Organizing Committee from the Union Nationale des Associations de Parents d'Enfants atteints de Cancer ou Leucémie (UNAPECLE)! Attendees were able to enjoy the city of Lyon which is known for its historical and architectural landmarks, as well as benefit from sessions that made Lyon the best CCI Congress ever!



Dr. Andre Ilbawi, MD, Technical Officer at the World Health Organization (WHO) gave the Keynote talk during the opening session. He reminded us of the joint vision we all share to cure all children diagnosed with cancer – a vision that is being implemented through the newly created Global Initiative for Childhood Cancer (GICC). Trained as a cancer surgeon at the University of Washington and MD Anderson Cancer Centre where he was involved in clinical and research efforts focusing on cancer care in low-resource settings, health system development, and strengthening cost-effective surgical services, Andre is the brains, vision and energy behind the WHO GICC and DEAR FRIEND OF CCI!

CCI's President, Ruth Hoffman shared personal thoughts during the opening session. She reminded us when a parent first hears the words that their child has cancer – their first thought is, **“Will my child die?”** What they are saying is, **“BUT – my child still has places yet to go!”** It is this reality that makes childhood cancer so difficult to accept because sadly more than 80% of our world's children with cancer do not get to live out the dreams of the places and things that they want to do in life. Those children who do survive live with the weight on their shoulders that the places they still have to go might be forever impacted by their cancer diagnosis and treatment. Ruth's daughter was once asked – “Who would you be if you were not a cancer survivor?” She responded with great insight that, **“Not knowing who she would have been is the biggest thing that she'd lost.”**



Adults diagnosed with cancer have experienced life. They have been places – they have graduated from school, had their first date, received their first paycheck, bought their first car. They have had a life before cancer and have an identity that is not connected to cancer. Children who have been diagnosed with cancer do not have that same “before.” The places they have still to go are all ahead of them. It is because we are united in this cause and committed to the vision that all children with cancer experience the places yet to go in their lives that we come together during the annual Congress.



CCI's Anniversary Annual General Assembly (AGA) was held on Friday October 25th at the Centre de Congrès, Lyon, France. Chaired by CCI President, Ruth Hoffman of the USA, and Secretary Luisa Basset of Spain, the Board of Trustees welcomed 26 full members and 6 associate members in attendance. Full member countries represented included: Ethiopia, Ghana, South Africa and Zimbabwe from Africa; China India, Indonesia, Israel and Japan from Asia; Austria, France, Germany, Ireland, Portugal, Russia, Spain and Switzerland from Europe; Argentina and Chile from Latin America; USA from the Americas and Australia and New Zealand from Oceania. Associate member representation was from Uganda, India, Iran, Lebanon, South Korea and Switzerland.

Voting with unanimous approval was recorded for the 2018 AGA minutes, annual report, Financial statements and auditor's report. Unanimous approval was also given for the extension for submission of the 2019 annual report, financial report and Board strategic plan.

We are pleased to report that members elected Daniel McKenzie (Zimbabwe) and Rodney Wong (Malaysia) to the CCI Board of Trustees.

The AGA closed with recognition of the enormous contributions made by Carmen Auste who had completed her 9 years of serving on the CCI International Board, followed by the sharing of the 25th anniversary cake!

BOARD OF TRUSTEES 2020

Ruth Hoffman, United States of America	President
João Bragança, Portugal	President-Elect
Luisa Basset, Spain	Secretary
Mary McGowan, Australia	Treasurer
Marcela Zubieta, Chile	Member
Nicole Scobie, Switzerland	Member
Carl Queiros, South Africa	Member
Daniel McKenzie, Zimbabwe	Member
Rodney Wong, Malaysia	Member



Simon Lala, (CFO), Luisa Basset, Marcela Zubieta, Mary McGowan, João Bragança, Ruth Hoffman with Andre Ilbawi, (WHO). Missing from photo: Nicole Scobie, Carl Queiros, Daniel McKenzie, Rodney Wong.

2019 MEMBERSHIP

North America

4 members
2 countries

4 full

Europe

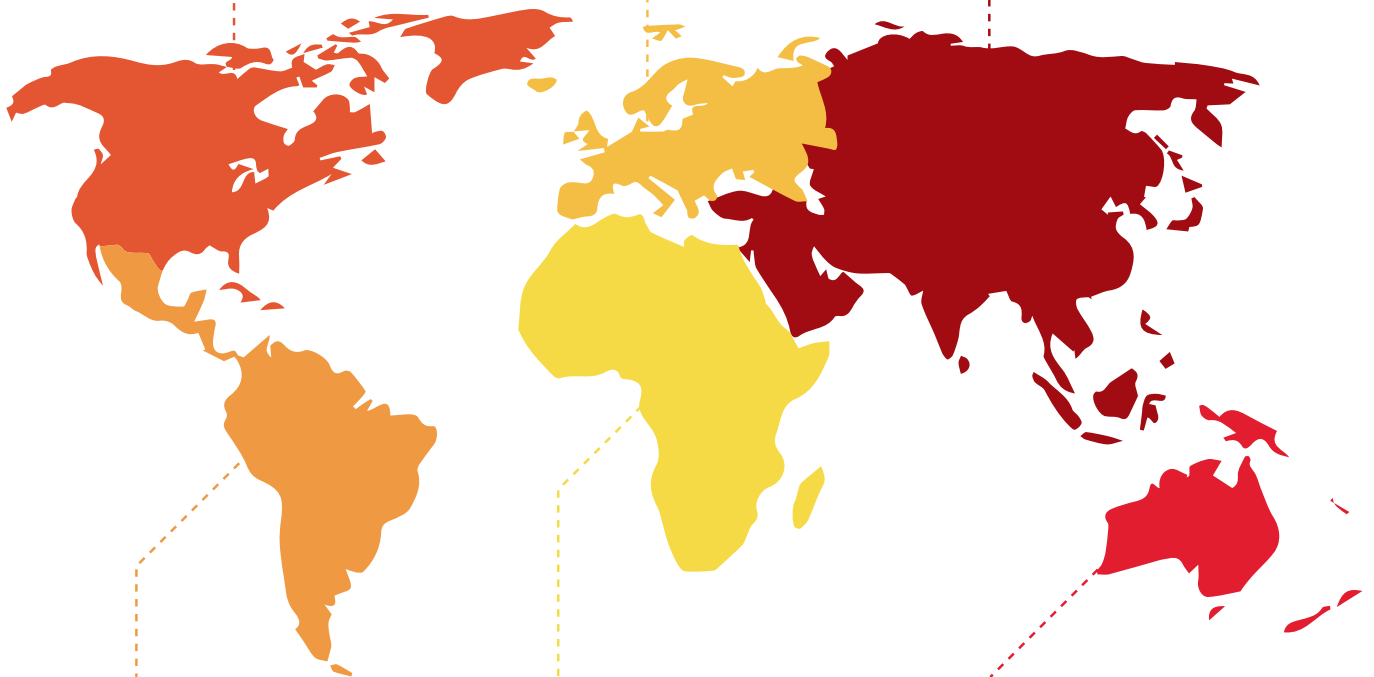
63 members
31 countries

46 full
17 associate

Asia

42 members
22 countries

15 full
27 associate



Latam

33 members
17 countries

16 full
17 associate

Africa

22 members
16 countries

8 full
14 associate

Oceania

3 members
3 countries

3 full

A F R I C A



Formed in 1994, CCI is recognised as the largest patient and family support organisation for childhood cancer in the world, with 167 member organisations from 90 countries. On the 31 January 2018, the World Health Organisation (WHO) set up an official relation with CCI.

CHOC has been a member of CCI since its inception 26 years ago, and CHOC is the Anchor organisation for CCI Africa. Our CEO, Carl Queiros, is the current chairman of CCI Africa, and a member of the international board. We play an important role for CCI regionally and internationally. The role of the Africa Regional Committee (ARC) and that of ours as CHOC, as the Anchor, involves building CCI in Africa, taking the cause of childhood cancer in Africa forward, and assisting in building the capacity of parent, survivor and childhood cancer organisations in Africa.

CCI Africa has 24 member organisations, representing 16 countries. Our goal is to work in partnership with international development organisations and range of stakeholders in childhood cancer towards:

- Reducing deaths from childhood cancer.
- Creating a supportive, enabling environment for childhood cancer initiatives.
- Improving equity in access to care.
- Transforming quality of care, including the provision of emotional and practical support to children with cancer, parent and families, in Africa.

Through our role in CCI we have been involved in a number of capacity building initiatives, a very good example of which is the Psychosocial training of psychologists and social workers from TAPCCO. TAPCCO is Ethiopia's Tesfa Addis Parents Childhood Cancer Organisation.

In January 2019, with funding support from the American Childhood Cancer Organization, the CHOC psychosocial training programme for TAPCCO involved the Ethiopian team spending time with the CHOC psychosocial team in the wards for a week; and then a week of theoretical training and input. This included comprehensive training of the whole role of the social worker, and specifically in paediatric oncology context. Among the best professionals in the field conducted the training, and the evaluation done at the conclusion indicated that the trainees greatly valued the training, and it was most useful.

Another highlight that should be noted, in terms of the CCI Africa advocacy goal, was that SIOP Africa and CCI Africa were invited to the meeting at the Africa Union gathering. The conference was held in Niamey-Niger from the 5 to 6 July 2019 which included the First Ladies and the African Heads of States. We presented the status of care of children with cancer and the urgent needs in Africa regarding paediatric oncology. The SIOP-CCI presentation was to a group of dignitaries and leaders that included many of the First Ladies, leaders of the health ministry of several countries, and a range of government officials. No doubt, this advocacy opportunity will raise the needs of childhood cancer treatment, care and support on the continent.

ADVOCACY

I'Association l'Avenir

Meeting with the representative of the WHO on November 2019, where we discussed the importance of social support to kids with cancer in the National Plan for Prevention and Control of Cancer 2020-2029.

Kayula Childhood Cancer Foundation

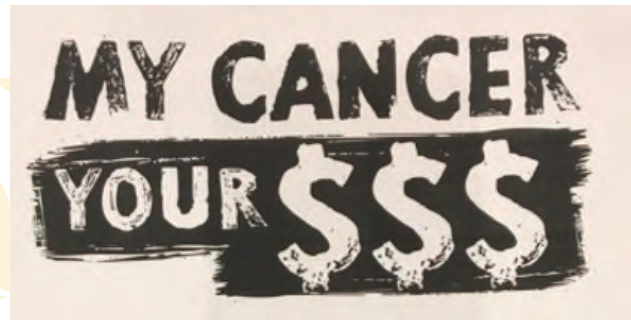
Meeting with the representatives of the WHO in February 2020, where we discussed quick wins for the organisation in terms of facilitating support such as transportation and permanent housing for the kids with cancer in the National Plan for Prevention and Control of Cancer 2020-2029.

Universal Health Coverage Day

Universal Health Coverage Day was held in December and was supported and promoted by many of the CCI Africa member countries.

World Health Organization

Cancer in the developing world is in a crisis and the most vulnerable and poorest do not have access to specialised treatment, essential medicine and care. Alliances, networks, trade unions, churches, and other civil society groups have come together in South Africa to say; “No more.”



During the 11th to the 13th of April 2019 the South African government hosted the World Health Organization second Fair Pricing Forum. Professor Janet Poole, Principal Paediatrician and Head of Paediatric Haematology / Oncology at Charlotte Maxeke Johannesburg Academic Hospital and CHOC Board member, as well as Adri Ludick, Programme Development Manager at CHOC attended an event where advocates from all over the world had a panel discussion about “No fair price without transparency”.



During the afternoon activists representing various cancer and civil society alliances and forums handed a letter to the SA Government, and worldwide representatives supported the action. We believe that if civil society stands together, we can reduce the exorbitant cost of medicine in developing countries and in general improve the lives of people battling cancer.

AWARENESS

Branding

With the goal of increasing awareness of CCI in Africa we produced CCI Africa letterheads, banners and t-shirts. These will be provided to all CCI Africa members to use at events, gatherings, for campaigns, at national and international meetings, and so on. Two CCI Africa banners were given to each member, and T- Shirts will follow.



All members are regularly urged to increase PR and spread awareness, to participate in campaigns such as ICCD, and to use the hashtag #no more pain. At the ARC meeting in Egypt Ruth offered to facilitate the creation of a CCI ARC Facebook page with approval from the board in Prague.



In Kenya

Hope for Cancer Kids (HFK), together with other Kenya Network of Cancer Organizations (KENCO), participated in the 4th February World Cancer Day which was held in in the Nairobi city centre. The team distributed brochures about the organization and its programs. Awareness was also raised on social media.



The funds drive ran on International Childhood Cancer Day (ICCD). In addition, much awareness was raised through television interviews on KBC and NTV. Throughout the year, other awareness raising events were held including a children's walk and schools events.



AWARENESS

In South Africa

CHOC in collaboration with the Eswatini (previously Swaziland) Department of Health, SNAP and partners like the Rocking Horse Project continues to raise awareness about childhood cancer and to demystify the myths and stigma related to the disease. We work together by taking action in saying; “No more!” An awareness campaign was launched during February with weekly articles in the local newspapers to inform the public about childhood cancer, stigma and referral pathways. CHOC also started a survey amongst the parents from Eswatini that are being treated in SA to establish what, and if any, the delays were in reaching help in time.



In South Africa CHOC continues to do training on the St Siluan Early Warning Signs of Childhood Cancer, which we have been doing since 2011 and have reached over 80,000 health care professionals and community members.

In collaboration with the Zambian Cancer Foundation, we trained nurses in July.

Additionally, CHOC continues with our formal and structured Awareness Training and Education Programme. To date we have trained over 25,000 healthcare professionals, healthcare workers, traditional healers and NGOs on the early warning signs of childhood cancer, nationwide. CHOC funds and supports the national childhood cancer registry (the SACTR). Prior to 2008, about 800 to 1,000 cases were reported to the SACTR annually, but in 2018 the new figures hit 1,500 – a 50% increase. We think this has a lot to do with CHOC’s early warnings signs programme.

In Nigeria

Simara Children Cancer Foundation’s awareness campaign and cancer education is one activity carried out every year and last year was no exception. The campaign involves: a neighbourhood enlightenment program, the promotion of the Saint-Siluan early warning signs of childhood cancer, lectures to care givers and social workers at hospitals, a cycling event entitled “Save a Child”, and oral presentations to the youth groups. Through this, Simara were able to increase the number of parents who bring their children to the hospital when some of the warning signs were noticed.



AWARENESS

Kidzcan Zimbabwe

Kidzcan continues to lobby to government and WHO to assist with allocating a small percentage of the Medicines budget from Ministry of Health for children with cancer. The 2020 Mudrun and our Orange Month in February raised great awareness for childhood cancer in Zimbabwe through participation, school and corporate engagement.



Kidzcan launched Orange Month on the 10th of February with an amazing event graced by the WHO Country Representative Dr Gasasira and the Vice President of Global Alliance from St Jude ALSAC Kim Humphries. International Childhood Cancer Day was celebrated with an amazing event in Bulawayo when Uncle Davey donated his beard with the proceeds coming to Kidzcan.

Alexandria Group of Childhood Cancer Care

A group of volunteers of our members of the group have been founded to supervise the activities in the Hospitality House for Cari Cancer Children and their parents and devoting their work for that purpose and we call them "Supervision committee". There was an upgrade of the kitchen to enhance preparing of meals for the cancer children and their mothers in the Hospitality House.

TAPCCO

Tesfa Addis Parents Childhood Cancer Organization

On February 15th, in collaboration with Wublink, Cocacoal and Abet Volunteers, we undertook an infection control campaign, cleaning the TAPCCO house, and teaching about the importance of hygiene and good sanitation in the fight against cancer. On February 14, we used Valentine's Day to foster love for children with cancer and raise awareness that children can have cancer too. We used Facebook to promote the cause and also raise egg donations in December 2019.

l'Association l'Avenir

There was a celebration of the International Cancer Day on February 15th. An open house was organized at the house of l'Avenir. The celebration was reported by different Medias (television, social media).

KCCF

Kayula Childhood Cancer Foundation

The first lady held a Private Sector stakeholders meeting for Breast and cervical cancer as well as other cancers that we got to interact with different organisations and advocate for support. Two weeks later, we attended the WHO workshop where our child Ambassador was given an opportunity to speak about her cancer survivor story.

CAPACITY

In the last quarter the main focus of the Africa Regional Committee (ARC) has been on holding its annual ARC meeting and assisting the SIOF Africa LOC in the planning and running of the parent and patient part of the CCI SIOF Africa Conference (both of which were held in Egypt).



The ARC meetings were attended by all of the ARC members (Carl Queiros (SA), Daniel McKenzie (Zimbabwe), Brain Walusimbi (Uganda), Prof Yasser Sadek (Egypt), Dr Kalagbor (Nigeria), Dr Ahenkorah (Ghana), and Sidney Chahonyo (Kenya). We also had two very special guests, namely our CCI President Ruth Hoffman, and Sara Ibrahim (Ethiopia).

I welcomed all and made some opening remarks. As chairman I gave a broad overall report of the CCI Africa developments and achievements over the last year. Of note was the partnerships between members such as CHOC and TAPCCO in Ethiopia; between Kidzcan Zimbabwe and Kayula Foundation in Zambia; and between CHOC and Cancer NGOs in Swaziland.

Each member was asked to give a short report on activities in the respective countries of origin. The most common challenges are: a lack of drugs, late presentations, stigma and the lack of government support.

The CCI President / Chairperson welcomed all and gave a report. Ruth explained the CCI structures, and advised about the next CCI board meeting in May 2019 in Prague. International CCI campaigns, and especially the WHO partnership was discussed in detail, with action items emerging. The three year WHO plan was discussed.

The ARC did an overview of the CCI Regional Committee Policy, discussed the key tasks of CCI regional committee, how to expand and strengthen membership of CCI in the region as well as to identify and nurture new partnerships.

The ARC plan to develop an ARC Regional Committee policy.

International funding for the CCI was discussed. Ruth talked about the disadvantages of CCI not fundraising, and the international partnership with Lions International.

In addition, we discussed the urgent need for pediatric palliative care in Africa, the reduction of pain, and especially the need to provide chemo-ports.

The ARC now meets regularly though conference calls every quarter, and once a year in person. The next ARC meeting will be in Ghana, West Africa, in April 2020. At the same event there will be a meeting for the leaders of all of the CCI Africa member organisations and will be called the CCI Africa Leadership Meeting. At this event there will also be some fundraising training.



Finance & Resource Mobilization

This last year CCI Africa had about 19,000 Euros in total (depending on the exchange rate) of which 10,000 Euros was committed by CCI International (5,000 from the previous year) and about \$9,000 by CHOC. All of the CCI funds are now used up, while only a portion of the CHOC funds has been used. We will now start using more of the CHOC funds.

At the ARC meeting funding was discussed in detail, including ideas for future fundraising. We need to be realistic though – everyone on the team is doing this in-between their other work, and all belong to organisations which themselves lack sufficient resources, and many organisations don't have great resource mobilisation capacity. Nonetheless, we hope to make some progress on this.

Of course all of the organisations have local fundraising /resource mobilisation to a lesser or greater extent. An example of this is in Egypt, where the Alexandria Group of Childhood Cancer Care (AGCCC) had a Fundraising campaign involving members/parents, volunteers and Rotary members of Alexandria Rotary Club, for the renovation of the out-patient clinic of the hospital.

CAPACITY

The Chair and Vice Chair (Carl and Daniel) attended the SIOP Conference in Lyon, where both participated in the CCI Board meeting, and Daniel McKenzie was appointed as a CCI Board Member.

Daniel represented CCI at the WHO Global Initiative Stakeholder workshops in Ghana and Zambia, as the two chosen demonstration sites for this WHO campaign.

Alexandria Group of Childhood Cancer Care

A share of 100,000 Egyptian Pounds (about 5000 Euro) has been offered through donations to Hospital of School Children to get a special apparatus for the clinical pharmaceutical assessment of the chemotherapy drugs given for the treatment of cancer children.

I'Association l'Avenir

A partnership with "Association Agir" (Casablanca) is under discussion.

TAPCCO

Tesfa Addis Parents Childhood Cancer Organization

Participated in 51st Congress CCI/SIOP in October 2019 at Lyon France.

Kayula Childhood Cancer Foundation

Collaborated with St. Jude Children's Hospital and the team from ALSAC and have begun training KCCF staff on how to fundraise.

Joint Fundraising Proposals

The CCI ARC looked into doing joint fundraising proposals and raising funds for CCI Africa in general, or for few members of CCI Africa, jointly. Various fundraisers were approached. Unfortunately we have hit two challenges. For one, the pool of funding for childhood cancer appears to be somewhat small. Secondly, the professional donors and consultants are not willing to do fundraising / put in proposals for us without payment up-front, or a clear (contractual) commitment to payment. As we don't have funds, this is not an option. We are in a catch 22 situation, but will keep exploring options.

I'Association l'Avenir

Fund given by Foundation Sixt (France) on November 2019, which allowed us to buy a bus to transport kids and parents from the house of l'Avenir to the hospital.

Kidzcan Zimbabwe

Elma has since increased our grant allocation to last until 2021.

We are currently applying to Oak for increased assistance as the organization is going National. London Children's Hospital has indicated a partnership on the Retinoblastoma campaign piloted with UNICEF in 2019. Local donors continue to assist Kidzcan with the Mudrun in January raising 738 000 zw dollars, with our Orange month expecting to double that for February.



TAPCCO

Tesfa Addis Parents Childhood Cancer Organization

Secured funding for medicine support for one year from Ethiopian Insurance Company with possible extension. Secured funding for one year for nutrition support from Turkish Agency called Hayrat Aid and Beka Ilim We Hizmet Dernegi. Secured local support for various needs. Sales tickets for support ranging from 10 Birr to 1000 Birr, the ticket also contains text about the curability of childhood cancer and the importance of early treatment.

RESEARCH

SIOP Africa and CCI Africa

SIOP in Developing Countries has a project to map all the services for children with cancer in Africa. The aim of this project is to create a baseline which can be used to lobby for improved services in both the local and global settings. CCI Africa members were asked to participate in this survey.

The SIOP PODC Patient, Family and Stakeholder Engagement Task Force includes Alta Bence from CHOC as a co-chair with Julia Challinor and Carmen Auste and the coordinator of Africa's participation in the study. South Africa (sponsored and represented by CHOC), Ethiopia and Morocco were the three African countries which participated and represented Africa in the above study.

Workshop October 2019

A five day workshop (17 to 21 October 2019) was convened in Lyon, France prior to SIOP/CCI 2019. Ten countries were represented at the workshop: Morocco, Iran, Albania, India, El Salvador, Peru, Mexico, Ethiopia, Georgia and South Africa.

The themes that emerged from the research are as follows: communication, loss, socio-economic impact (finances), diagnostic itinerary (timeline in getting a diagnosis), length and complexity of treatment process and the community (positive and negative experiences of a sense of community).

Next In Process

- A full data analysis to be done by each researcher in the project.
- Based on the full data analysis each country need to decide on how they wish to use the material – e.g. publish a paper locally
- Explore publishing a paper based on the collective data analysis.
- Explore working with the various themes in different working groups.

In addition several countries have plans to work on and/or participate in local research projects.

MEMBERSHIP

TAPCCO

Tesfa Addis Parents Childhood Cancer Organization

Applied for CCRDA (Consortium of Christian Relief and Development Aid) membership, already in the process of acceptance to secure funding, training and network with different organizations.

PARTNERSHIP

SIOP Africa and CCI Africa

The ARC met with the SIOP Africa committee to discuss our partnership. This was a very positive meeting where much was discussed. In short we basically discussed ways of greater collaboration and future plans. Key points or decisions made are:

- CCI Africa will have two permanent representatives on the SIOP Africa committee, which automatically will be the Chair and Vice-Chair.
- We discussed collaboration involving our relationship with the WHO.
- We discussed our participation in a potential upcoming Africa Union event involving first ladies.
- We discussed the impact of having a clear parent and survivors' voices at various forums and at all levels.
- We discussed in-depth the upcoming SIOP Africa event to be held in Uganda (2021), including the improvement of the application process for a host nation, ensuring CCI Africa coordinates the parent track (not left up to the host nation only), and that as both SIOP And CCI have a presence African wide, our partnership should be African wide as well. With regards to SIOP Africa in Uganda, our ARC member Brian, will be part of the LOC.

Ghapacc

Ghana Parents association for Childhood Cancers was represented at the SIOP meeting in France in Oct 2019.

Kidzcan Zimbabwe

ALSAC/St Jude has been mentoring Kidzcan Zimbabwe in capacity building on fundraising since 2018. This has resulted in increased income for all our activities despite the economic constraints. Kidzcan visit St Jude twice a year and last did so in December 2019 for the St Jude Marathon Workshop. As a result the Vice President of St Jude Global Alliance Kim Humphries visited Zimbabwe on the 9th of February 2020. The Executive Director attended the WHO Global Initiative in Zambia and Ghana representing Kidzcan and CCI. Participation in SIOP 2019 in Lyon enabled Kidzcan to create new partnerships and is awaiting delivery of chemotherapy drugs from Idi by month end.

I'Association I'Avenir

Connection with ALSAC who is drafting a Regional Conference agenda for 2020.

CHOC

CHOC/ SA is working in collaboration with number of sister parent and cancer organisations in neighbouring countries and other countries: Eswatini, Lesotho, Ethiopia and Zambia; with some some discussion for potential collaborations with Botswana and Namibia. These are around: awareness raising, nurse training in the early warning signs, and the training of social workers.

TAPCCO

Tesfa Addis Parents Childhood Cancer Organization

TAPCCO continues to have an effective partnership with the Ministry of Health, where we work closely to monitor the supply of essential medicines, as well as quality treatment and care. Through our attendance at conferences and childhood cancer workshops we are able to learn from other organizations such as the American Cancer Society. We are grateful for our partnerships with the ASLAN Foundation and the American Childhood Cancer Organization who provide funding for many of our programs including patient and family nutritional support, as well as staff salaries.

Kayula Childhood Cancer Foundation

Connection with ALSAC who is helping us review our Strategic Plan going forward, implementing training and ensuring we try new ways of approaching donors.

O C E A N I A



Oceanic and Southwest Pacific Report

This region remains small with only three full members as part of the Childhood Cancer International family. With changes to the regional structures, there will be more members.

In 2019 we had our inaugural Parents Day sponsored by New Zealand Child Cancer Foundation. It was a very informative day attended by over sixty parents from Australia and New Zealand and has laid good groundwork on which to move forward.

The Foundation in New Zealand has been very involved in increasing the care offered to patients and families in Fiji. During the past twelve months they have been actively supporting a regional outreach paediatric oncology nurse in her community work with families.



The Child Cancer Foundation has funded a research project, in collaboration with CureKids, to develop a precision medicine protocol for difficult-to-diagnose-and-treat cancers. The Foundation increased their overall commitment to this five-year project to \$1,375,000. It is hoped that this translational project will build capability in the New Zealand pediatric oncology research sector as well as giving more Kiwi children the opportunity to be included in trials.

Victoria has continued to work closely with fortnightly regular teleconference meetings with the Paediatric Oncology team while setting up in Papua New Guinea. They have also continued with regular telephone meetings with the team in Laos.



CCI-Europe Regional Committee (ERC)

The Vision of CCI Europe to cure children and adolescents with childhood cancer with no- or as few as possible long-term health problems and late-effects continued in 2019. To reach its vision, close collaborations with the medical and psychosocial professionals, academia, scientists, the civil society and private organisations all over Europe were further strengthened. A highlight in this regard was a joint conference by SIOP Europe and CCI Europe in May 2019. Also, 2019 had a strong focus on survivorship and highlighted what is still to be done for better quality of life of survivors.

CCI-Europe Committee members

Austria **Anita Kienesberger (Head of Committee)**
Österreichische Kinder-Krebs-Hilfe

Spain **Luisa Basset**
Federación Española de Padres del Niños con Cáncer

Bosnia and Herzegovina **Lejla Kameric**
Udruženje "Srce za djecu koja boluju od raka u FBiH"

Sweden **Holly Wattwil**
Barncancerfonden

Switzerland **Nicole Scobie**
Zoé4life

Luxembourg **Anne Goeres**
Fondatioun Kriibskrank Kanner

France **Frédéric Arnold**
UNAPECLE

Netherlands **Jaap den Hartog (Survivor)**
Vereniging Ouders, Kinderen en Kanker' (VOKK)

Austria **Carina Schneider (Survivor)**
Österreichische Kinder-Krebs-Hilfe

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ADVOCACY

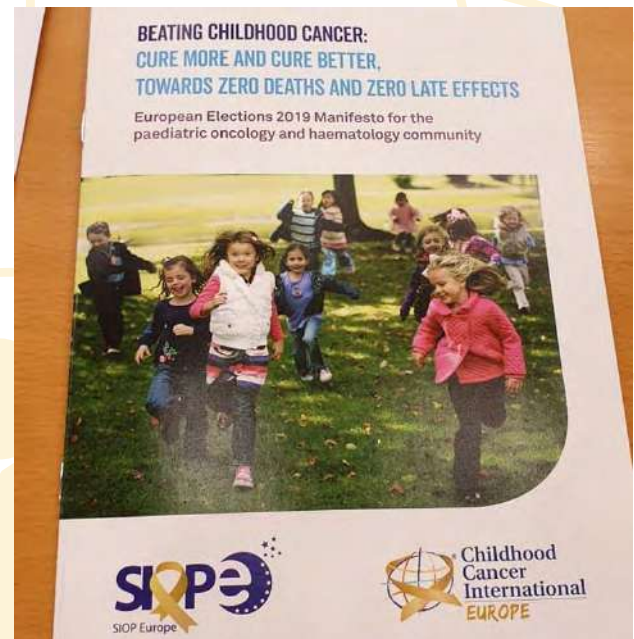
The 6th March 2019, in an event at the European Parliament, hosted by MEP Elena Gentile (S&D, IT) and organised by SIOP Europe, CCI Europe and SIOP Europe presented the European Elections 2019 Manifesto: “Cure more and cure better – Towards zero deaths & zero late effects.”



With the beginning of the year, CCI Europe deepened its advocacy for establishing comprehensive long-term follow-up care for childhood cancer survivors across Europe. At International Childhood Cancer Day (ICCD), the awareness campaign #Raiseyourhands4survivors was kicked off which lasted until the end of the International Childhood Cancer Awareness Month in September. A petition for better long-term follow-up care across Europe was launched, with the goal to present it in the European Parliament at the following ICCD 2020. Stay tuned for next year to find out how it turned out.



The successful completion of the EU Joint Action on Rare Cancers was celebrated after three years of activity during an event about the Rare Cancer Agenda 2030 at the European Parliament.



AWARENESS

The CCI campaign #nomorepain for the International Childhood Cancer Day (February 15th) was shared on the CCI-Europe Facebook page, inviting the European members to participate. The campaign was translated into different languages (Greek, etc).



Furthermore, CCI Europe dedicated the year 2019 to the Survivorship Campaign #Raiseyourhands4survivors, which was launched also at the International Childhood Cancer Day. Knowledge about late-effects of treatment and cancer is often rare among survivors and many healthcare providers. Survivor-representatives within CCI Europe were voicing the need for more information about late-effects and structures for long-term follow-up care.



Two awareness movies about survivorship issues were created in partnership with the ERN PaedCan: The first movie specifically addresses the lack of long-term follow-up structures, the second movie focuses on the importance of informing childhood cancer survivors about possible late-effects early on. Both movies can be seen here: <https://ccieurope.eu/about/>

With the support of BAYER ph., CCI Europe was invited to present the two movies at the ESMO conference, quotes and parent/survivor experiences as well as the work of CCI Europe. In addition to the movies, which reached thousands of people, an online petition was started in order to increase awareness about childhood cancer survivorship.



The new CCI Europe website was launched in May 2019, where latest activities and regular updates of EU projects are broadcasted. Check it out at www.ccieurope.eu

CCI Europe also sent its first Newsletter in the beginning of October 2019 to all CCI Europe members and partners.

CAPACITY

10th CCI Europe Regional Conference

The 10th CCI Europe Regional Conference took place from May 22-24, 2019 in Prague (Czech Republic). The conference was held in conjunction with the first edition of the SIOP Europe Annual Meeting (May 20-25, 2019), bringing together researchers, clinicians, young investigators, healthcare professionals, policymakers, parents, patients' representatives and survivors.



CCI members had the opportunity to attend the whole conference-week, to network, exchange and gain new insights and knowledge - not only within the CCI community but throughout the whole childhood cancer community!



Wednesday, May 22, was a joint day for all participants, with plenary sessions including all expert groups. Amongst them, the CCI Europe Roundtable discussions "Opportunities for collaboration between patient representatives and medical healthcare professionals" and "survivor's journey - looking back into the future" had a big audience. On Thursday and Friday, the CCI Europe Regional Conference took place. The program comprised joint sessions, workshops and presentations highlighting the needs of patients, survivors, and parents across Europe and CCI Europe members supporting initiatives.

WECAN Course

Three members from CCI Europe selected by WECAN participated at the Start Smart Advocacy course, taking place in Frankfurt in July 2019. The CCI Europe project manager participated at the WECAN/ESO Masterclass from July 7th until July 9th.

Resource Mobilization

CCI Europe received funding from Novartis for the CCI Europe Survivors Network and the CCI Europe Conference 2020. On the other hand, Servier is supporting CCI Europe in 2019 to participate at webinars and f2f meetings, to support the development of questionnaires and patient information and to review the patient informed consent. CCI Europe was able to showcase its work and the survivorship awareness movies at the Bayer booth at the ESMO (Barcelona September/October 2019), as well as putting Flyers at the booth and presenting their work. CCI Europe also received support from the "Fondatioun Kriibskrank Kanner" for training activities and awareness, as well as smaller contributions through the CCI Europe website.

RESEARCH

ERN PaedCan

European Reference Network in Paediatric Oncology

In 2019, three ERN PaedCan meetings took place, both were very fruitful in terms of collaboration: CCI Europe talked about the importance of parents/patients and survivors involvement regarding clinical guidelines and showcased our work to the attending health care professionals. With 5 representatives participating, CCI Europe made the parents', patients' and survivors' voice heard very clearly.



Harmony

Healthcare Alliance for Resourceful Medicine Offensive against Neoplasms in Hematology

Harmony evolved through an EU project and is a public-private network. It focuses on re-using anonymous data and developing a secure infrastructure to store the data. CCI Europe is involved in the topics of patient consent and data confidentiality. In June, the Alliance announced that its innovating Big Data Platform was ready to meet its milestone of capturing anonymized data records from 45,000 patients with blood cancer. It is expected to reach 100,000 patient records until 2021. CCI Europe is included across all relevant Working Groups.

JARC

Joint Action on Rare Cancers

CCI Europe was included intensively in the Childhood Cancer Work Package and has been working on the JARC book, which was finalised and presented at the European Parliament in September 2019. It contains 10 chapters for policy makers and each chapter containing one targeted policy recommendation on rare cancers, including a dedicated section on specific priorities in childhood cancers, which are all rare. This very important booklet is available online and also in hard copy: <https://ccieurope.eu/download/>

PanCare FollowUp (PCFU)

The kick-off meeting of the new EU-funded PCFU project took place from January 14th - 15th, 2019 in Amsterdam. This project will last for 5 years and will develop a blueprint for how to best deliver person-centred follow-up care. A working group meeting for developing follow-up guidelines in plain language, took place from February 26th – 27th 2019. In September, CCI Europe was supporting the Work Package leaders in creating and conducting 3 Focus Group Discussions with parents and survivors during the PanCare meeting in Basel. Around 10 participants took part per Focus Group. Furthermore, CCI Europe started to work on setting up content for the project website and creating information materials for survivors regarding late-effects and follow-up. The second PCFU meeting took place in June 2019 in Amsterdam and in October another guideline workshop to further advance the development of follow-up guidelines.

PARTNERSHIP

PanCare

Pan-European Network for care of survivors after childhood and adolescent cancer

PanCare is actively working on reducing the frequency, severity and impact of late side-effects of the treatment of children and adolescents with cancer. CCI Europe is working with PanCare in the area of survivorship care. Two PanCare meetings took place in April and September 2019.

SIOP Europe

European Society in Paediatric Oncology

CCI Europe and SIOP Europe have established a memorandum of understanding in the areas of Research and Development, access to standards of care and expertise, social sciences and ethics and the improvements to the regulatory and political environment at pan-European and national level. The joint SIOP Europe annual meeting/CCI Europe Conference was another huge milestone in the fruitful collaboration between the two societies.

Memorandum of Understanding

between SIOP Europe, PanCare and CCI Europe

In order to join forces in improving the quality of survivorship, SIOP Europe, PanCare and CCI Europe signed a Memorandum of Understanding in September 2019. One important project that the three societies have committed to work on in close collaboration is the Europe-wide implementation of the Survivorship Passport.

EURORDIS

Rare Disease Europe

CCI Europe is collaborating with EURORDIS especially within the European Reference Networks (ERNs) and the Joint Action on Rare Cancers (JARC), having established a very good working relationship in the past years. EURORDIS ePAG f2f meeting took place, where the focus was on patient engagement in ERNs.

ECCO

European Cancer Organisation

ECCO is the only multidisciplinary organisation connecting all stakeholders in oncology Europe-wide. CCI Europe is representing the paediatric parents' and survivors' interest through its participation in the ECCO Patient Advisory Committee (ECCO PAC).

WECAN

Workgroup of European Cancer Patient Advocacy Networks

WECAN is a network of leaders of cancer patient umbrella organisations active in Europe. Its mission is to strengthen patient advocacy in Europe and improve outcomes for all cancer patients. Through WECAN, CCI Europe is able to collaborate with other European cancer patient organisations, exchange knowledge and develop joint projects. Furthermore, the network provides valuable resources for CCI Europe members to obtain knowledge (i.e. through training courses).



In the 2019 CCI Conference in Mexico, members established Regional Commitments and tasks objectives in Member Regularizations, Survivor Network, Public Policies, Institutional Strengthening, Finance, and Communication.

The **Member Regularizations** Target is to establish a member representative by country to contact organizations in an irregular situation and to promote the incorporation of new members.

The **Survivor Network** Target is to invite Latin American survivors to the CCI Latam 2020 conference. Know their stories and explain to them the importance of following up.

The **Public Policies** Target is to push for more advocacy on local childhood cancer issues.

The **Institutional Strengthening** Target is to continue the application of the Institutional Strengthening Survey, which establishes levels in: transparency, efficiency and governance of CCI Latam organizations.

The **Finance** Target is to share models to raise funds.

The **Communication** Target is to establish a CCI Latam website and social network.

Four Initiatives Highlighted This Year

Educational campaign of the symptoms of childhood cancer early detection in Honduras

a strategy by the Honduran Foundation for the Child with Cancer (HFCC)

Catasterismi, Winning Instinct

a play written and performed by Mexican childhood cancer survivors

Strengthening CCI member institutions in Latin America

The experience of the Honduran Foundation of Children with Cancer in the process of implementing the Institutional Check List

The LATAM Survivor Network

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CATASTERISMI, WINNING INSTINCT

A play written and performed by Mexican childhood cancer survivors.

This staging by a group of young survivors of childhood cancer has been presented in different stages and cultural spaces, bringing its transforming message of love for life to over 900 people.

The play exposes the reality of living with a cancer diagnosis and the vision acquired by young patients when going through such an experience. The plot develops in an outpatient chemotherapy room, where the characters meet and share their experiences. The stories shared are real life stories of the young actors, their feelings, thoughts and reflections about life and faith while facing cancer.



This play was born from the desire to share a message of strength, hope and faith, brought to the audience by this group of cancer survivors. They open their hearts to share a part of their struggle with the intention of transmitting their love for life.

Catasterismi means: “The transformation of a person into a star”, a word full of meaning for those who experience cancer closely, thus becoming the title of the play, in honor of all those who are not with us but who became stars.

This unprecedented play in Latin America is written and starred by childhood cancer survivors who participate in the Mexican organization CANICA AC : Alondra Castillo (germinal tumor in the pineal gland), Belén Rivero (ALL), Gema Landeros (ALL), Monserratt Ogaz (papillary and follicular carcinoma), Carlos Frías (ALL) and Vanesa Mancilla (ovarian dysgerminoma). They decided to share their experiences and learning acquired during their cancer treatment to leave an important and transformative message in the minds and hearts of those who attend this wonderful play.

The play has been presented nine times in Jalisco, Mexico in different stages, as well as a presentation in the framework of activities of the 17th Congress of the CCI Latam held in Urubamba, Peru. The performance creates a magical experience in each presentation, leaving the audience with a strong feeling of reflection and love for life.



MEMBERSHIP

The experience of the Honduran Foundation of Children with Cancer in the process of implementing the Institutional Check List

CCI member organizations in Latin America have different institutional development levels; they also differ in the spectrum of benefits granted to children with cancer and their families. Even more, there are countries where there is no public policy coping with childhood cancer. Therefore, the work of parents' organizations in our Region becomes more relevant.



With the aim of strengthening existing institutions an initiative was developed. The purpose was to enhance their capacities in their administrative, legal, service delivery and fundraising efforts. The goal was for existing institutions to become more efficient and at the same time transparent and accountable for the State, donors and the society in general.

To achieve this goal, 3 years ago FNH designed a certification process. Organizations interested in getting certified chose to participate in this process. The initial instrument used was an Organizational Check List that revised their administrative, legal, service delivery and fundraising processes, among others.

During the XI CCI Latam Meeting in Mexico 2019, the Honduran Foundation for Children with Cancer took on the challenge of participating in this initiative. Dr. Marcela Zubieta visited Honduras to learn about the work and experience of this organization and to carry out an integrated approach to the certification process. After that, the organization started the process of collecting information and filling out the forms required for assessment and review.

This second stage, done completely online, has had the participation of Mr. Carlos Sánchez - Project Coordinator of the organization and Elizabeth Campos Ramírez, Organizational Strengthening Consultant, who is pro-bono supporting this process.

The Honduran Foundation has delivered all the documents requested and fulfilled all the requirements for this process. Their administrative capacity has been approved and certification has been granted.

It is important to note that this organization has an outstanding track record and it is recognized in the country for its contributions. They submitted all their supporting information to demonstrate that they meet the criteria of the checklist. As pioneers, who successfully completed this process, and once the CCI Committee has approved their application and results; the Honduran Foundation for Children with Cancer will receive the Golden Ribbon Certification at the Next Meeting in 2021. This is the highest recognition that an organization can aspire to within this process.



SURVIVOR NETWORK

In Latam there are many challenges to support children with cancer and their families, among them, the challenge of creating a network of cancer survivors in Latin America.

During the XI CCI Latam Conference (2019) we started this process with a conference by Dr. Annette Becker, Pediatric Oncologist with over 20 years of experience in monitoring children with cancer. She talked about the importance of educating on the different aspects of life after cancer treatment.

Throughout the year we contacted different organizations in Latam, encouraging them to contact childhood cancer survivors interested in creating a network. Eleven young survivors from 6 countries participated the XII LATAM Conference held in Peru. They came from Mexico, Colombia, Honduras, Bolivia, Ecuador and Chile, and their ages fluctuated between 18 and 31. On average 10 years had passed since their first diagnosis.

The activities started with a panel moderated by Yolima Méndez from Colombia, the survivors shared the challenges they had faced after surviving this disease. After that, they participated in a focus group, where they shared their concerns and fears. Although they came from different places and realities, they had many things in common, and shared similar feelings towards life after cancer and their own future. After that, by mutual agreement they adhere to our proposal of creating a Latam network of childhood cancer survivors. The purpose of this network is to share personal experiences, support their peers, children in treatment and their families.



Among the many issues discussed, the most important for them is the need to obtain complete medical information of their treatment. In many pediatric oncology units patients are discharged 5 years after diagnosis without an adequate summary of their medical history and no clear information regarding the side effects that may occur in the future.

Another objective of this network is to create a platform where survivors can obtain bio psychosocial information validated by health care providers working in childhood oncology. This platform would guide patients and /or their families regarding their health related concerns.

After the conference, all the members of this new network were highly motivated to continue working in this project from their respective countries. This network is expected to develop as part of the CCI organization, which will help them to spread their message and create awareness among childhood cancer survivors from the whole continent. They expect to have an impact in the lives of many survivors and become agents of change in the future.





CCI Asia Regional Committee (ASRC) members

Hong Kong China **Benson Pau**
Pau Kwong Wun Charitable Foundation

Egypt **Manale Elewah**
Art2Care

India **Bindu Nair**
Aroh-Giving Hope

India **Poonam Bagai**
Cankids...KidsCan

Philippines **Carmen Auste**
Cancer Warriors Foundation

Lebanon **Roula Farah**
CHANCE Association

Malaysia **Gary Ho**
Sarawak Children's Cancer Society

Japan **Kazuyo Watanabe**
Asian Children's Care League

Indonesia **Ira Soelistyo**
Yayasan Kasih Anak Kanker Indonesia

Iran **Saideh Ghods**
MAHAK

UAE **Sawsan Abdul Salam Al Madhi**
Friends of Cancer Patients

Portfolios

Head of Committee
Benson Pau

Finance & Resource Mobilization
*Sawsan Abdul Salam Al Madhi
and Poonam Bagai*

Capacity Development

Regional Conference / Meeting
Gary Ho

**Membership Development &
Data Management**
Ira Soelistyo and Kohsuke Yamashita

Developing Parent Groups in Asia
Carmen Auste and Manal Elewah

Asia Survivor Group Development
Poonam Bagai and Roula Farah

**Strategic Partnership
& Awareness**
Carmen Auste and Kazuyo Watanabe

Communications & Awareness
Bindu Nair and Roula Farah

Research
Roula Farah and Saideh Ghods

ADVOCACY

WHO Global Initiative for Childhood Cancer Workshops

Myanmar: Benson Pau and Carmen Auste represented CCI participating in the 2nd Myanmar National Workshop on the Childhood Cancer Control Programme on 8 May in Yangon and 9 May 2019 in Nay Pyi Taw. Carmen was the moderator for the “Implementation Needs” session and Benson joined the panel discussions of “Health System Needs” and “Programmatic & Policy Levers” sessions.

Philippines: Carmen Auste represented CCI participating in the National Stakeholder Workshop on Childhood Cancer in Manila on 25 September 2019. She was one of the moderators during the Open Discussion session of “Supporting National Priorities through Action”.

WHO Regional Office

Poonam Bagai represented CCI participating in the WHO South-East Asia Regional Workshop in New Delhi on 25-26 June 2019 and was invited to speak on childhood cancer and present the work of Cankids in pediatric oncology. Ms Ritu Bhalla, childhood cancer survivor, delivered a speech “Remarks by a prominent cancer survivor” at the Opening session.

Vietnam Cancer Control Consortium

Carmen Auste was invited to participate in the Annual Scientific Conference on Cancer Control in Hue on 29-30 August 2019. Due to other engagement, Benson substituted Carmen to attend the conference and made a presentation on “How to Treat and Care Cancer Patients : A Patient-Centered Approach.”

Cancer Warriors Foundation Inc

Cancer Warriors Foundation co-founded Cancer Coalition Philippines which crafted the National Integrated Cancer Control Act (NICCA). The Bill was signed into law by President Rodrigo Duterte on 14 February 2019. The Act covers all cancers for all ages and gender.



It aims to strengthen health system capacities and increase resources allocated for cancer care and cure. It also introduces initiatives that lessen various forms of burden that cancer patients, people living with cancer, survivors and their families face. Palliative care and pain management programs as well as patient navigation and child life services will be mainstreamed in all levels of care. Although the scope is all cancers, it is a big step forward to improving availability, affordability, access and quality of childhood cancer care services. The Philippines’ NICCA experience has been recognized by UICC with Philippines choice as Treatment for All site and Cancer Warriors selection as Country Champion for the Philippines. NCD Alliance has also included this in a global compendium of successful advocacy initiatives from 10 countries.

AWARENESS

CCI Asia Newsletter

Thanks to the great effort of editorial team led by Bindu Nair and Roula Farah with contribution from ASRC and CCI Asia members, the first edition of CCI Asia newsletter was launched in early January 2020 with tight schedule after the discussion of ASRC in Lyon annual conference for CCI Asia newsletter.

Ugam's 10th Anniversary Celebrations

On 2nd of June 2019, Ugam celebrated its 10th anniversary on occasion of World cancer survivor's day amongst 350 guests of which 200 were cancer survivors who travelled from many states of India! Ugam is a voluntary support group which helps childhood cancer survivors to rise above all obstacles in life & be VICTORS!



This event is a celebration of life and a beacon of hope for the survivors, their friends and supporters and the entire society. This celebration is to spread awareness and create opportunities to facilitate their life's journey on the correct path and in the right direction. The theme for the 10th Anniversary was Partnership – with donors / hospitals/ institutes /volunteers helping in empowering Ugam.



The event featured a skit highlighting body image issues of survivors and an informal interview with married survivors with their spouses. The event was highlighted in print media.

Ribbons of Hope

National School Awareness Campaign

In 2019 in Lebanon, the CHANCE (Children Against Cancer) Association organized several events of significant importance, the most remarkable of which was that relating to the School Awareness Campaign. Because early diagnosis saves lives, the team at CHANCE Association launched a nationwide campaign entitled "Ribbons of Hope" in public and private schools, in order to raise awareness on the early signs and symptoms of childhood cancer. Hence, CHANCE President, together with the team of Volunteers visited several schools in various regions across Lebanon. Colorful awareness cards were distributed to parents, and creative fun activities around the yellow ribbon were shared with the children in their classrooms.



This campaign had an incredibly positive impact nationwide. It supported educating hundreds of families about the presenting symptoms of childhood cancer, in addition to smoothly transmitting the message of hope.

Sarawak Children's Cancer Society

Stem cell donation has the potential to help save lives of children affected by childhood cancer. The diversity of race and intermarriage among Malaysians however, means that the probability of finding a matching donor for most patients, is very low. At the beginning of 2019, there were only 725 registered stem cell donors from Sarawak. The Society sought to change this, and, seeking the help of various local community groups, organised 6 stem cell donor drives in 2019, signing up 311 potential donors. We're continuing this mission in 2020, and with support from the public, we'll be able to give children with cancer a better chance at survival.

CAPACITY

Palliative Care Clinic

On May 20th 2019 ASHIC launched Bangladesh's first "ASHIC Mobile Pediatric Palliative Care Clinic" (ASHIC Mobile PPCC). Funded by a grant from NVIDIA, a U.S. technology company, the Mobile PPCC will provide transportation services and other facilities for 2 years to an estimated 600 children living in rural areas, accompanied with a community awareness campaign.

The uniquely fitted ambulance has already provided transportation to more than 100 cases of palliative patients within the city, and back to their rural homes. Transport is also provided for deceased children, to be taken to their home villages for proper burial rites.

MAHAK

MAHAK has assessed its Project, Program and Portfolio (PP&P) processes and structures according to an international standard which is the Delta Assessment model. It is the only NGO in the world that has volunteered and exposed its processes to this high-level assessment and achieved the third level of this standard in its first trial and audit. It should be noted that only 10% of the organizations which have had the same experience have been able to achieve the third level of Delta model in their first audit.

Asian Children's Care League (ACCL)

ACCL has been partnered with Hue Central Hospital (HCH) -Vietnam since 2005 to carry out the childhood cancer project through the holistic, dynamic and sustainable approach that encompasses both medical and social dimensions. In December 2019, the very first successful stem cell transplant was performed at Pediatric Center's Transplantation Unit which ACCL supported. Thanks to all the medical staff of HCH, the experts - local and international, the donors who brought this milestone of treatment improvement come true.



Hope to bring more hopes and smiles to children with cancer and their families with continued optimal treatment and compassionate care.

Shine On! Kids

SOK's Hospital Facility Dog program pairs a dog specially trained to work at a children's hospital, with an experienced nurse trained to be the dog's handler. They work full-time at a single hospital as part of the medical team supporting the care of pediatric oncology and other very ill patients. Until now, SOK's dogs were trained in the US, but in order to create sustainability and meet increased demand, SOK began training on their home ground in Japan in 2019!



Above: Our HFD candidates, Ty and Masa.



Above: Annie, our HFD at work at Kanagawa Children's Medical Center.



Above: Mayuko Ohashi, the Handler at TCMC, thoroughly sanitizes the child's hands before and after the interactive session with Ivy, the Hospital Facility Dog.

CAPACITY

Hair For Hope

Mooted by nine CCF (Children's Cancer Foundation) volunteers in 2003, Hair for Hope (HfH) has become CCF's signature community outreach event to raise childhood cancer awareness and funds.



Held for the 17th consecutive year, Hair for Hope 2019 raised an unprecedented \$4.78 million in donations with 5,456 shavers parting with their locks to tell children with cancer that it is OK to be bald. Besides the main event held at VivoCity, 52 satellite events were also held at corporate offices, schools, public agencies and grassroots organisations. It was also the first time that the campaign was fronted by a celebrity ambassador, Andie Chen.

Friends of Cancer Patients

Young social advocates aged 19 – 30 in the UAE will undergo intensive capacity building training to lend their voices to the noncommunicable disease (NCD) dialogue, under the two-year Young Leaders Program (YLP), launched by UAE-based non-profit, Friends of Cancer Patients (FOCP) in partnership with NCD Child. The first-of-its-kind program seeks to generate much-needed awareness on NCDs among the young generation, paving the way for their sustained involvement in global NCD processes and research. The program recognises the youth's great potential as agents of change, and follows the vision of Her Highness Sheikha Jawaher bint Mohammed Al Qasimi, Wife of the Sharjah Ruler, who has leading efforts in advocating for youth-inclusive policies.

Parent Group Development

Yangon, Myanmar: For on-going support of the Golden Hands of Hopes (GHH), the parent group under Yangon Children's Hospital, and Global Initiative for Childhood Cancer matters in Myanmar, Carmen Auste visited in February, and both Benson Pau and Carmen Auste visited in May 2019 again. GHH is steadily growing with regular meetings supported by a local person paid by CCI.

Mandalay, Myanmar: Though with several visits to Mandalay Children's Hospital since 2016, development of parent group in Mandalay is slow.

Hanoi, Vietnam: Benson Pau made his second visit to Hanoi in August 2019 meeting with the medical team and parents in Vietnam National Children's Hospital. On-going festival events were held in the childhood cancer ward of the hospital.

Hue, Vietnam: The formation of Family Group of Hue Central Hospital was started with encouragement of CCI and Kazuyo Watanabe of ACCL, Japan years ago. Benson Pau made a follow up visit to Hue in August 2019. The lead person of the Hue Family Group moved to other city for his new job so the group was slowed down in 2019.

Nutrition Program in Myanmar

CCI in collaboration with Boston Children's Hospital were supporting a Nutrition Program in Yangon Children's Hospital Hematology/Oncology Unit in 2019 and it will be continued into 2020.

Sarawak Children's Cancer Society

During our 2018 visit to the CCI annual international conference, Dayang Zubaidah, a 2-time childhood cancer survivor, met other survivors from the world over, who had formed survivor groups in their own countries. Meeting them made her realise that survivors still need much support and education, even after treatment. With the help of SCCS, she and other survivors came together to form Heroes of Hope (HoH), and since then, they have been carrying out activities at the ward to bring joy and hope to the fighters.



Activities such as peer to peer sessions with the fighters and their parents, to provide moral support, and also joining classes for self-improvement, are all in line with their mission of supporting survivors and fighters, as well as continuously developing personal and professional skills. Says Md Fahkri, in charge of Development, "Being a survivor inspires me to support all kids in fighting cancer. Joining HoH gives me the chance to do this, and make a difference."

RESEARCH

Survivor and Parent Engagement in Childhood Cancer Treatment in Iran

A research study has been conducted by MAHAK at the national level aiming to understand the needs and expectations of the patients/survivors and their parents during the cancer treatment journey and also to document their perceptions about being involved and engaged during this journey. Utilizing a qualitative method approach to examine neglected aspects of this journey, it was found that lack of effective communication skills especially with the medical team, the dominance of a medical approach instead of a multidisciplinary approach, and the absence of pediatric psychology support were the most important obstacles for a successful engagement of patients, survivors and parents through cancer treatment journey.

PARTNERSHIP

Children's Cancer Center of Lebanon

As a pioneer for the treatment & care of kids with cancer, and in an effort to foster partnerships and enhance national cancer advocacy in Lebanon, July 2019, the Children's Cancer Center of Lebanon (CCCL) initiated the Lebanon Cancer Cooperation (LCC) which is a network of over 20 NGOs dealing directly or indirectly with cancer control in Lebanon.



The framework for the LCC network will include national cooperation for capacity building, public awareness and advocacy in support of cancer patients in Lebanon. The CCCL has led networking efforts for the LCC and also built official bridges with the Ministry of Public Health to facilitate action plans.

N • A M E R I C A



North America Regional Report

Canadian report submitted by
the Kids with Cancer Society of Northern Alberta



It is my pleasure to submit this report to Childhood Cancer International, on behalf of the Kids with Cancer Society of Northern Alberta. Respectfully submitted by Val Figliuzzi, Executive Director Kids with Cancer Society of Northern Alberta and a parent of a survivor of childhood cancer.

United States report submitted by
the American Childhood Cancer Organization



Advocacy has been at the heart of the American Childhood Cancer Organization's (ACCO) mission since the organization was founded in 1970. Fifty years later, ACCO is still leading the way in advocacy at the state and federal level as well as around the world. We are proud to be the U.S. member of CCI and proud of the following 2019 accomplishments.

ADVOCACY

Advocacy in Canada

Advocacy initiatives are identified in partnership and consultation with the pediatric oncology medical team, Family Advisory Council, Board of Directors and most importantly the families that we serve.

The Family Advisory Council meets quarterly to identify issues that need to be taken forward. These include lobbying for fertility issues, egg retrieval and access to government support programs. In addition, the Family Advisory Council was successful in advocating for, and allocating increased budget funding to research programs as well as the creation of a PTSS program.

Advocacy will be an important stream in our strategic plan that is currently in the development phase. We believe that any advocacy issue must be carefully planned and executed, and to take forward only those issues that are critical to the wellbeing of the pediatric oncology population. We need our voices to be heard when and where it matters the most.

U.S. President's Childhood Cancer Data Symposium

ACCO CEO Ruth Hoffman and Director of Government Relations and External Affairs Jamie Bloyd were pleased to be among a very few parent advocates selected by the NIH/NCI CCDI team to attend the private President's Childhood Cancer Data Symposium in Washington, DC. ACCO also co-authored a paper that was selected for poster presentation regarding state-level funding that resulted in the discovery of a cluster of pediatric brain tumors in Kentucky.

U.S. Center for Disease Control

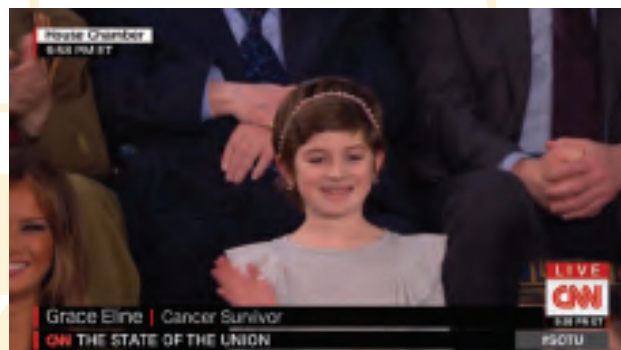
It has long been a priority of ACCO to raise awareness for the importance of states including specific childhood cancer objectives in state cancer action plans. Unfortunately, 29 states still have no mention of childhood cancer and the process for updating plans can be a sluggish, multi-year process requiring a skilled local advocate familiar with navigating within a variety of structures in state coalitions. To change this statistic, ACCO has developed relationships with and continues to travel to Atlanta, Georgia to meet with CDC leaders regarding implementation of the surveillance portion of the Childhood Cancer STAR Act (including how to more effectively track issues of long-term survivorship) and inclusion of childhood cancer in state cancer action plans.

U.S. Department of Health and Human Services

ACCO has been honored to meet with top leadership at the U.S. Health and Human Services department in Washington, DC. Secretary Azar and Admiral Giroir expressed particular interest in our work at the global level as well as at the state-level. We strongly believe our leadership at the initial meeting impacted the decision for the President to announce his new Childhood Cancer Initiative.

U.S. State of the Union

In early 2019, ACCO led efforts to coordinate logistics with the White House for Amazon + ACCO ambassador and New Jersey childhood cancer survivor Grace Eline to be featured in the President's State of the Union address. Grace had the opportunity to sit with the First Lady as the President announced plans for a historic \$500 million in new funding for the Childhood Cancer Data Initiative; an NCI led collaboration to build a data ecosystem so that every child's diagnosis counts towards much needed scientific research breakthroughs.



U.S. Action Days 2019

ACCO was proud to join hundreds of children and family members impacted by a childhood cancer diagnosis on Capitol Hill for Action Days 2019 as we advocated for full funding for year two of the Childhood Cancer STAR Act legislation making it easier for children with complex diseases to seek care across state lines, and increases in overall funding for the National Institute of Health and National Cancer Institute. ACCO was pleased to visit with U.S. Senate Majority Leader Mitch McConnell in his Capitol office and thank him for his leadership in securing unprecedented funding for childhood cancer research.

ADVOCACY

USPS Semi-Postal Stamp

For more than 10 years the breast cancer stamp has raised hundreds of millions of dollars to revolutionize breast cancer research. With that model, ACCO took the lead and presented the final application for a childhood cancer semipostal stamp to the General Counsel of the USPS. To date more than 15,000 letters of support have been submitted to demonstrate broad public appeal of the fundraising stamp. We are hopeful that a childhood cancer semipostal will be unveiled in December 2021 at a national ceremony to be organized by ACCO.



ACCO also organized the 3rd PJammin at the Mansion for more than 50 children and family members impacted by childhood cancer at the Kentucky Governor's Mansion on October 25, 2019.



U.S. State Proclamations

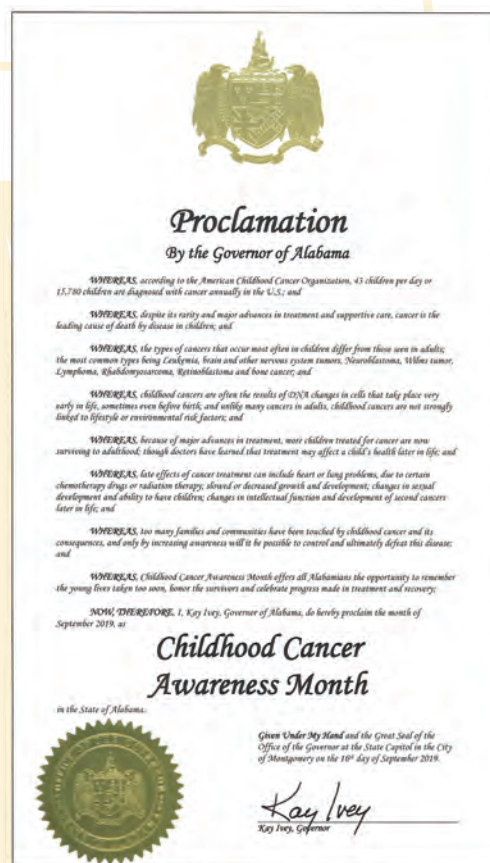
Together with grassroots advocates and organizations across the country, ACCO led the way in securing state proclamations for September Childhood Cancer Awareness Month from governors across the United States.

Why Not Kids?

While momentum towards childhood cancer as a top national child health priority has accelerated dramatically since December, ACCO has simultaneously been aggressively pursuing progress at the state level.



With most state legislative sessions starting in January, we kicked off the year organizing and traveling to attend state awareness days in five states (Kentucky, Texas, Pennsylvania, Virginia, New Hampshire, and New Jersey).



AWARENESS

Awareness in Canada

In addition to our monthly television spots, social media platforms, and general awareness campaigns, we continuously strive to identify ways to increase our community reach. One of our main goals has always been to differentiate ourselves from adult cancer organizations such as the Canadian Cancer Society, local children's hospital foundations, and pop up charities.

We also see awareness as an important strategy to ensure that all families diagnosed with cancer in our region are aware of, and have access to our services. This is accomplished through the relationship that we have at the hospital that submits referrals to our organization so that family visits can be initiated. Following the initial diagnosis, we have support counsellors who connect with families on an ongoing basis to ensure that they are aware of all of the programs and services that are available to them at no cost. We believe that all families in our region should have equal access to all of the supports and services that we provide.

U.S. Amazon GO GOLD® 2019

Building on historic Amazon + ACCO GOES GOLD in September with campaigns from 2017 and 2018, the GOES GOLD 2019 kick-off 'Fireside Chat' took place in Seattle on September 6th. Throughout the month, Amazon GOES GOLD went global with fulfillment centers from around the world partnering with local non-profit childhood cancer research organizations to benefit children and families impacted by a childhood cancer diagnosis. For the third year, Amazon turned shipping materials into awareness tools, sending millions of packages emblazoned with the gold ribbon - the official symbol of childhood cancer.



U.S. Awareness Tree

Each year ACCO decorates a 20-foot tall tree with thousands of gold ribbons, each bearing the name of a child who has been diagnosed with cancer. The tree is an integral part of the Newport Beach Boat Parade which has been in existence for more than 100 years. Since 2000, ACCO has honored and commemorated tens of thousands of children.



Public Relations in Canada

This is an area where growth is required as too often other projects have taken priority.

We tackled this challenge by revamping our website, which continues to be a work in process, and engaging in a robust social media plan.

CAPACITY

Resource Mobilization in Canada

In 2019 we hired several additional staff members with an objective to increase our fundraising capacity as well as expanding program delivery. In 2019 we achieved unprecedented success raising more funds than ever before in our history, and creating new programs including PTSS support, outreach programs and additional research grants.

Educational Materials in the U.S.

ACCO continues to be the leading publisher and distributor of free childhood cancer educational materials. Written and produced for children with cancer and their families, ACCO's informational resources cover the spectrum from disease specific materials to psychosocial support, pain management and even a play therapy toolkit. Tens of thousands of children and their families benefit from ACCO's free resources each year.



Financial assistance and face-to-face support is provided through ACCO's chapters called Founding Hope. Each program assists families with specific regional needs to provide much needed support along the childhood cancer journey.

RESEARCH

Research in Canada

In 2019 we increased our research support grants by 300%. Several new grants were awarded with a 5-year commitment totalling \$600,000. per year. These included funds to support DIPG/brainstem glioma, osteosarcoma, reducing clotting risk in pediatric cancer patients and linking factors in the environment to causation of childhood cancer as well as access to clinical trials. However, given the economic climate we will need to pause several of these grants for 2020.

In closing on behalf of the Kids with Cancer Society I would like to extend my thoughts and best wishes to all of our friends across the world who are dealing with COVID-19 and its effects both on their families and their work with children with cancer.

PARTNERSHIP

Membership Building in Canada

As noted in previous reports as we meet families at the time of diagnosis, and given there is only one treatment center in Northern Alberta, we do not face challenges building our membership. One exception is building a database for the survivor population which has proven to be problematic simply because parents are our main contact and are often reluctant to provide contact information on their adult children.

We have made progress through a partnership with the Kids with Cancer Society Childhood Cancer Survivors program, at the hospital, and have embarked on a project that focuses on the needs of survivors. This is, and will be a work in progress which we consider critical given the emerging needs of survivors, and this growing population.

International Reach

ACCO is proud to be in partnership with Sick Kids Hospital, Toronto as the fiscal sponsor of the ACCESS East African Research Project. Advances in childhood cancer care have made cure a reality for over 80% of children in high-income countries (HICs). These advances have not translated into many systems of care in low- and middle-income countries (LMICs), where the burden of childhood cancer looms largest.

A major impediment to the effective care of children with cancer in LMICs is lack of access to essential medicines. To bridge existing knowledge gaps on childhood cancer drug access in LMICs and in partnership with Sick Kids Hospital, Toronto, we launched a multi-center study in Kenya in September 2019 with the following aims:

- To understand the challenges related to childhood cancer drug access in East Africa.
- To leverage this knowledge to inform and catalyze coordinated procurement of childhood cancer medicines in the region.

Ultimately, our goal is to equip local stakeholders with policy-relevant data to improve access to essential cancer medicines for children and adolescents with cancer in LMICs.

In addition to our research funded work in 5 East African Countries, ACCO continues to fund essential hospital programs in Addis Ababa, Ethiopia. Working alongside TAPCCO, ACCO provides funding to enhance their nutrition program and in-hospital psychosocial care.



Nairobi Inaugural Regional Stakeholder Meeting

“Oh the places you’ll go...”

*You’ll be on your way up!
You’ll be seeing great sights!
You’ll join the high fliers
who soar to high heights.*

*You’re off to Great Places!
Today is your day!
Your mountain is waiting.
So... **get on your way!***

- Dr. Seuss

As the largest grassroots organization in the world representing the families of children with cancer, it is our hope and vision that all children grow up and experience the things they dream to do, and the places they dream to go.

CCI looks forward to the next 25 years and to ensuring that dream becomes a reality for all children with cancer regardless of where they were born, or live in the world.

**- Ruth Hoffman, President, and the
2019 CCI Board of Trustees**





Advancing Cure, Transforming Care
for Children with Cancer, Survivors and Their Families

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