



Childhood
Cancer
International

Annual Report 2018



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Childhood Cancer International Applauds World Health Organization's New

Global Childhood Cancer Initiative

Each year around the world, there are more than 300,000 children diagnosed with cancer, with an additional estimated 100,000 children undiagnosed. More than 80% of these children live in low-to-middle income countries, where approximately 80% of them will die.

In 2017, during the 70th World Health Assembly (WHA) held in Geneva, Switzerland, the World Health Organization's (WHO) 2017 Cancer Resolution was unanimously adopted by WHO Member States. This resolution, which was an update from the 2005 WHO Cancer Resolution, challenged member states to address the inequity in access to treatment, with an emphasis on outcomes for all people living with cancer, including the special population of children, adolescents, and young adults.

With this mandate, in 2018, the WHO launched the Global Initiative for Childhood Cancer. Its goal is to support governments in building and sustaining high-quality childhood cancer programs.

The Target Goal of the WHO Global Childhood Cancer Initiative is to achieve at least 60% survival for all children with cancer by 2030.

This represents an approximate doubling of the current cure rate and will save an additional one million children's lives over the next decade.

Childhood Cancer International is proud to be a Non-state Actor in official relations with the WHO. Comprised of 171 member organizations in 88 countries around the world, we are the largest organization representing the voice of the families of children with cancer. As such, we play a major role in the translation of this target goal into the concrete actions needed to save our children's lives.

“The world is full of frameworks, roadmaps and action plans that sit on shelves collecting dust, and never making a difference to people. I urge you, starting now, to translate your good intentions into concrete actions that transform the health of your people.”

- Dr. Tedros, Director General, World Health Organization

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Message From Our President



The year 2018 began with an historic milestone for Childhood Cancer International (CCI). In January, the World Health Organization's Executive Board admitted CCI as a non-state actor into official relations with the WHO, making CCI an official WHO Ambassador. This honor came as a result of years of working alongside the WHO, including collaborative in-country work in Ghana, Ethiopia, Myanmar and Fiji.

As the global voice of the parents and families of children with cancer, CCI is uniquely positioned to identify the needs of children diagnosed with cancer from those who have "walked the walk." In collaboration with the WHO, our voices are strengthened as we advocate together to leadership around the world to ensure childhood cancer is a local, national, and global child health priority.

"Civil society partners are unique and powerful voices of the people that WHO serves. Their valuable resources, knowledge and close community connections can help WHO ensure our impact is much greater than when we act alone."

Dr. Tedros, WHO Director-General

The continuing status of maintaining official relations with the WHO is governed by the Framework of Engagement and the creation of a 3-year collaborative work plan with agreed upon objectives and activities. The WHO-CCI's plan includes ongoing in-country work in Myanmar, Ethiopia, and Ghana and is focused on the following four major areas that greatly impact childhood cancer in those target countries.

WHO - CCI 3-Year Work Plan has 4 General areas of intervention:

1. **Palliative Care and Pain management:** using the WHO guidelines to train parents in its use;
2. **Nutrition:** development of a tool to better understand childhood cancer nutritional gaps/needs;
3. **Psychosocial Support:** establishment of parent and caretaker support groups globally to enhance support for parents of children with cancer;
4. **Advocacy:** collaboration of key childhood cancer messaging and advocacy efforts including common global messaging during International Childhood Cancer Day (ICCD).

On February 15th—International Childhood Cancer Day—in keeping with our 3-year plan and as part of our advocacy communications, CCI launched year #1 of a 3-year social media campaign called #nomore. This year’s key message, entitled: #nomorecomplacency focused on the need for action. Materials were developed using WHO resources that highlighted survival disparity for children with cancer in low-middle income countries (LMICs) vs. high-income countries (HICs). These assets were distributed to CCI members around the world and were translated into different languages for circulation to families, governments, civil society, and international development institutions, encouraging them to “Act Now” as there can be #nomorecomplacency for children with cancer and their families.

Through CCI’s enhanced engagement with WHO, CCI continued to strengthen our relationships with our collaborative partners including SIOP, UICC, NCD Child, ICPCN (International Children’s Palliative Care Network), the Maruzza Foundation, and St. Jude’s Children’s Research Hospital.

On June 4th, in Vienna, we continued to expand our partnerships with the signing of a cooperative agreement with the International Atomic Energy Agency (IAEA). This new partnership will enable the IAEA to better provide access to diagnostic services and radiotherapy to treat children with cancer in LMICs. Working together, CCI and the IAEA will raise awareness, advocate to government, and mobilize resources to benefit children with cancer in IAEA Member States.



Ruth Hoffman, President, CCI, and Dazhu Yang, Deputy Director General of the International Atomic Energy Agency’s (IAEA) Division of Technical Cooperation sign partnership agreement.)

It was appropriate that it was during September Childhood Cancer Awareness Month that the year’s momentous events culminated. Following a late August strategy meeting hosted at the WHO headquarters in Geneva, CCI was invited to represent the voice of the families at the official launch of the WHO Global Childhood Cancer Initiative which was held at the UN General Assembly in NYC. It was there, CCI had the opportunity to express our gratitude to the UN member states from the Republic of Uzbekistan, Jordan, Philippines, Russia, El Salvador, Moldova, Morocco, and the United States for their leadership and vision in hosting what we will all remember in our lives as an historical UN General Assembly side-event on childhood cancer.

We applauded WHO leadership for their vision to save an additional one million children’s lives by 2030 through the attainment of a 60% global childhood cancer survival rate—a goal to be accomplished through increased prioritization of childhood cancer at the global and national levels, and expansion of the capacity of countries to deliver best practices in childhood cancer care.

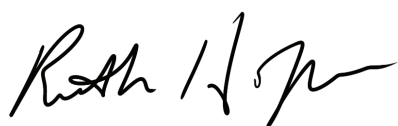
Our main message however, was the reminder of the power of the parent voice as a global army and ally in reaching this target to double the overall cure rate of childhood cancer and to eliminate all serious health-related suffering that accompanies this devastating disease in our children.

It has been through the combined efforts of CCI members and childhood cancer parents around the world that childhood cancer has become a WHO child health priority. It was parents in 1998 who created the gold ribbon symbol for childhood cancer—a symbol which has now been embraced around the world. Parents shaved their heads to raise money for research; they wrote books explaining what clinical trials were and why they were so important for children to be part of - even if they knew their own children wouldn't benefit. Parents went to local governments with innovative ideas to increase funding for research, and incentives for industry to produce new childhood cancer drugs. Parents held events in China, Indonesia, Bangladesh, India, and other countries to raise funds to build homes-away-from home and pay for the salaries of the pediatric oncologists in their countries. They provided money for bus tickets in South Africa so that children could get to the hospital and not abandon treatment; they paid for food in the hospital in Ethiopia to ameliorate the comorbidity of fighting malnutrition and childhood cancer together.

Parents have translated the early warning signs of childhood cancer into more than 40 different languages and distributed the information to community health workers in low-middle income countries to promote earlier diagnosis; they have created an International Childhood Cancer Day in February and proclaimed September as Childhood Cancer Awareness Month in countries around the world. They have hung gold ribbons from parliament buildings, lit up Niagara Falls, the Sydney Opera House, and the Taj Mahal gold. They have engaged the schools their children attend; and the companies where they work. It was parents who partnered with the richest man in the world, Jeff Bezos, so that he would wear his pajamas to an Amazon board meeting and tweet out to the world that he did that to honor the lives of children who fight cancer in their pajamas each and every day.

Through CCI members and parents around the world, we have created and led a global childhood cancer movement and our key message is the reminder of the value of ensuring that parents are engaged as equal partners in the work that we will continue to do together through this WHO Global Childhood Cancer Initiative—whether they be from high-income or low-to-middle income countries. It is parents of children with cancer who have “walked this walk,” and it will be the inclusion of the parent voice in the Global Initiative that will lead to the doubling of the global cure rate.

On behalf of the CCI Board of Trustees, I want to express my deepest gratitude for the endless and selfless work that is accomplished by each of you to benefit the hundreds of thousands of children with cancer, survivors, and their families who you serve each and every day. Each CCI member organization has a reach to hundreds, and thousands and even tens of thousands of parents and families whose children have been diagnosed with cancer. It truly is an army—an army who, together with our partners, can translate our good intentions into concrete actions to save an additional one million children's lives in the next decade.



Ruth I Hoffman, MPH
President, Childhood Cancer International

Board of Trustees

Approved in Kyoto at the CCI Annual General Assembly

Ruth Hoffman (USA) President, parent

João Bragança (Portugal) VP, parent

Luisa Basset (Spain) Secretary, parent

Mary McGowan (Australia) Treasurer

Carmen Auste (Philippines) parent

Marcela Zubieta Acuña (Chile) parent

Nicole Scobie (Switzerland) parent

Carl Queiros (South Africa) member

Simon Lala, CFO

Lex Kuiper Office management 10 hours/week



This picture was taken in Kyoto in November 2018. Carl Queiros and Nicole Scobie were not present at the time.

World Health Organization & CCI

As of January, 2018, CCI is in formal official relations with the World Health Organization.



EXECUTIVE BOARD
142nd session
Agenda item 5.5

EB142(9)
26 January 2018

Engagement with non-State actors

The Executive Board, having examined the report on non-State actors in official relations with WHO, including the review of one third of the non-State actors in official relations with WHO,¹

(1) decided:

(a) to admit into official relations with WHO the following non-State actors: Association Africaine des Centrales d'Achats de Médicaments Essentiels; Bloomberg Family Foundation, Inc.; Childhood Cancer International; International Society of Paediatric Oncology; IOGT International; KNCV Tuberculosis Foundation; Médecins du Monde; Osteopathic International Alliance; PATH; Public Services International; The Wellcome Trust; and United States Pharmacopeia Convention;

(b) to discontinue official relations with the following non-State actors: European Centre for Ecotoxicology and Toxicology of Chemicals; Foundation for Innovative New Diagnostics; International Federation of Business and Professional Women; and Rehabilitation International;

(2) noted with appreciation their collaboration with WHO, commended their continuing dedication to the work of WHO, and decided to renew in official relations with WHO the 66 non-State actors whose names are listed in Annex 2 to document EB142/29;

(3) further noted that plans for collaboration with the following entities have yet to be agreed, and decided to defer the review of relations with CBM; CropLife International; International Agency for the Prevention of Blindness; International Air Transport Association; International Association for the Study of Pain; International Eye Foundation; International Network for Cancer Treatment and Research; International Society of Physical and Rehabilitation Medicine; Project ORBIS International, Inc.; World Blind Union; and World Council of Optometry until the 144th session of the Board in January 2019, at which time reports should be presented to the Board on the agreed plans for collaboration and on the status of relations.

(Twelfth meeting, 26 January 2018)

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¹ Document EB142/29.

Global Context

Global Goals



Access to Increased
Survival Rates



Access to Essential
Medicines



Access to
Quality Care



Elimination of Suffering &
Palliative Care

“Too many children have had their lives cut short by cancer, and survival rates in poor countries are scandalously lower than those in wealthy countries.”

- Tedros Adhanom Ghebreyesus, director-general of the World Health Organization

Global Objectives

- Increase political commitment and capacity of countries to deliver best practices in childhood cancer diagnosis and treatment;
- Support governments to develop high-quality cancer centers as well as develop standards and tools to guide the planning and implementation of interventions for early diagnosis, treatment, and palliative and survivorship care;
- Improve access to affordable essential child cancer medicines and technologies;
- Support governments to safeguard families of children with cancer from social isolation and financial ruin as a result of cancer care;
- Prioritize cancer as a child health priority and increase available funding at the national and global levels.

CCI Members 2018

It is through the work of the 171 Member Organizations of Childhood Cancer International across 88 countries that we are able to “*translate our good intentions into concrete actions that transform the health of our children.*”

WHO Regions

WHO Member States and corresponding CCI members are grouped into 6 WHO regions: Region of the Americas (**PAHO**), African Region (**AFRO**), South-East Asia Region (**SEARO**), European Region (**EURO**), Eastern Mediterranean Region (**EMRO**), and Western Pacific Region (**WPRO**).

The following regional summaries on pages 11-29 highlight

CCI Member Concrete Actions



Drive
Advocacy



Intensify
Awareness



Strengthen
Parent Groups



Mobilize
Support



Nurture
Partnerships



Set Up Supportive
Structures

CCI MEMBERSHIP 2018



PAHO Region of The Americas

34 members

18 countries

18 full

16 associate

EURO European Region

71 members

33 countries

54 full

17 associate

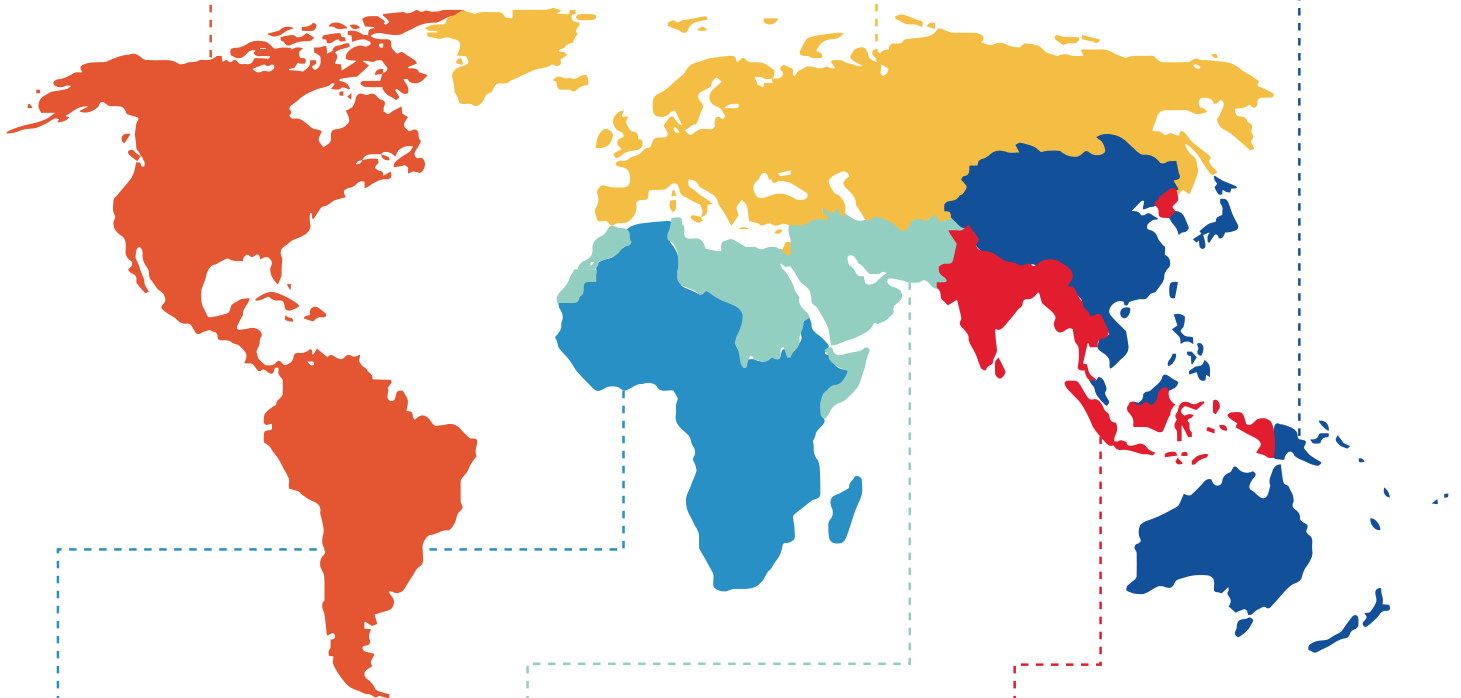
WPRO Western Pacific Region

16 members

10 countries

8 full

8 associate



AFRO African Region

20 members

14 countries

9 full

11 associate

EMRO Eastern Mediterranean

13 members

8 countries

1 full

12 associate

SEARO South-East Asia

17 members

5 countries

7 full

10 associate



United States



🗣️ Advocacy

Why Not Kids is the American Childhood Cancer Organization’s state-level advocacy campaign, an initiative based on successful efforts in Kentucky, that focuses on working with state governments to close the gap between budget allocations that go towards adult versus childhood cancer research.

In the 2018 Kentucky legislative session, Governor Matt Bevin and the Kentucky General Assembly recognized this urgent need and set a national precedent for state engagement in the fight against childhood cancer by appropriating \$5 million dollars for collaborative childhood cancer research efforts, focused on promoting scientific advancements utilizing immunotherapy and molecularly based treatment.



“If state funds have been allocated to adult cancer research – why not kids?”

🕒 Awareness

In September 2018, ACCO and Amazon joined forces for a second year to GO GOLD® with a multifaceted campaign to transform public awareness of childhood cancer as a national child health priority. In addition to 10 million shipping boxes and packaging raising awareness of the gold ribbon symbol for childhood cancer, Amazon wrapped an Amazon Prime Jumbo Jet with ACCO’s registered trademark GO GOLD®!



💰 Resource Mobilization

In the summer of 2018, the STAR (Childhood Cancer Survivorship, Treatment, Access, and Research) Act of 2018 was passed into law. The STAR Act of 2018 authorizes Congress to allocate \$30 million annually for 5 years into pediatric cancer research including bio-banking and survivorship studies.



👨👩👧👦 Parent Groups

ACCO recognizes that families whose lives had been impacted by childhood cancer often want to honor their child’s legacy by helping people in similar situations. Traditionally, this resulted in many small childhood cancer charities being created in a child’s name.

Families informed us that they, “simply want to spend their time focusing on making a difference.” Instead, they found themselves bogged down with the headache and hassles associated with the administrative responsibilities that accompany the formation and ongoing operation of their own non-profits.

Our Founding Hope program empowers individuals to work under ACCO’s Federal ID number in the process of establishing their very own local program. In addition to providing the charitable structure and recognized ACCO name and brand to assist with the individual’s charitable goals, ACCO also provides a custom webpage, a user-friendly donation page, a peer-to-peer fundraising platform and a designated staff person to give direction and take care of the time-consuming administrative duties required by the IRS. Every chapter is unique; families are encouraged to name their own fund, develop strategic goals, and decide how to allocate donations to best serve the childhood cancer needs in their geographic area. In 2018, ACCO worked with families to establish 35 Founding Hope Chapters in 19 states across the country.



*Report submitted by the Kids with Cancer Society of
Northern Alberta, Edmonton, Alberta Canada*

Advocacy

In 2018, advocacy continued to be an important part of our mission. We acknowledge that children are underrepresented in all aspects of cancer care and research and want to take action. Although our involvement to date has been limited, due to a small staff, we started to work towards ensuring that children with cancer and their families have a voice. As an example we advocated for our membership through our involvement in the “Partnership Against Cancer” movement.

Our membership also identified fertility treatment as an issue, and our goal is to partner with other groups to advocate for funding for survivors of childhood cancer.

In conjunction with September Childhood Cancer Awareness Month we were also involved in the annual CureFest event that advocates for increased funding for pediatric cancer issues. This included lighting public buildings, media releases, and communication with local government.

Supportive Structures - Research

Our involvement in supporting research increased in 2018. This included a \$3 million-dollar research endowment chair, support of clinical trial access, recruitment of fellows, and general research programs.

Awareness

Each month we were fortunate to be featured on a local television station where we provided information about our Society and featured one of our stories. Through this medium we increased awareness within our community, evident by increased donations and general support.

Social media is also one of our priorities and we worked with a local company to create a robust social platform.

All efforts were made to connect with families at the time of diagnosis to provide information about our services. We remain one of the only organizations in Canada that receives referrals from the hospital when a child is diagnosed with cancer, which initiates a hospital visit.

Resource Mobilization

As a growing organization, we recognized the need to increase staffing to improve access to programs and increase funding. We hired an additional fundraiser and administrative support to combat the challenges associated with the downswing in the economy.

We identified ways to sustain our programs through the creation of annual gifts, monthly giving, bequests, and general donations. In addition, we embarked on renewing our strategic plan and created a solid business plan.

Parent Groups

We believe that communications involve two audiences – families and community.

To increase our presence and improve communications we updated our website, created a detailed communication plan, and created ongoing dialogue with families including newsletters, mailouts, and program information.

The Society provided more than 50 programs, at no cost to our membership. In 2018 alone, our services were accessed more than 4500 times. Programs included support activities, financial support, educational support, counselling services, mentoring, and short-term overnight accommodation.

Partnerships

As we meet families at the time of diagnosis, and as there is only one treatment center in Northern Alberta, we do not have any challenges building our membership. However, what we found is that we were unable to build a database of survivors as they transitioned into adulthood. Often parents are reluctant to share information on their adult children and our ability to communicate directly with this population was limited. To address this issue, we began working with the survivor program at the hospital to collect contact information for survivors so that we can offer programs.

We are also rebuilding our database that will enable us to communicate more efficiently with our membership. This includes updating contact information and identifying the medical status of the child.

CCI LATAM: Regional Report 2018

It is the second year of the new CCI Latam Regional Committee. It fulfills its objective of boosting the actions of CCI in the region, increasing the involvement and participation of organizations, teamwork, improvement in internal processes, regulating the role of the committee, and increasing the number of members to strengthen the regional network.



Structure of the Committee

- Marcela Zubieta - Board Member International - Chile
- Yolima Mendes - Colombia
- Ximena Castellanos - Bolivia
- Elizabeth Campos - Executive Secretary - Colombia

Oscar Barbaste from Fundación Nuestros Hijos continued as a communication link between the Region and the international level, and was linked with Javier Galván from the Canica Foundation of Mexico for the organization of the 2019 Meeting.

Rules and Processes

The Committee developed a Rule of Stipends and the Process for the Organization of the Regional Conference to clearly establish the guidelines for each of the topics.

Periodic Meetings and Delegation of Functions

Each member of the Committee has tasks and commitments, based on their strengths, to improve the work of the region, in addition to the responsibilities and local commitments of each member with their own foundations.

Regional Survey

In order to report our actions, we conducted a survey during the Regional Meeting in Puerto Vallarta (May 2019) where we surveyed 22 organizations from 7 countries. The following pages will detail the results.

Advocacy

41% of all foundations reported advocacy efforts, including participation, elaboration or support for proposals presented in our work sessions and Senators' chamber, among others.

The Honduran Foundation for Children with Cancer presented a proposal designed to ensure that children from Quintana are treated in Cancún, as well as a care initiative in the ambulatory ward of the general hospital.

The Nuestra Esperanza Foundation in Bolivia presented a proposal of support and follow-up for cancer patients in states of vulnerability and risk, with the objective of reducing situations of conflict that may occur with patients from dysfunctional homes.

The Divina Providencia Foundation of Cali, Colombia supported the creation of a social diagnostic, considering the latent needs in each context in the field of childhood cancer.

Chile participated in the creation of the Law of Leave for the Caretaker: Ley Sana ("Healthy Law"). Chile also participated in working sessions for the elaboration of the Cancer Law and the National Cancer Plan. Marcela Zubieta, President of Fundación Nuestros Hijos was invited as the only speaker outside of the President of the Republic in the launch of the law in La Moneda, House of the Government.

The Sanar Foundation and Colombia Foundation of Leukemia and Lymphoma in Colombia developed advocacy tasks through the Inter-Institutional Observatory of Childhood Cancer ("Observatorio Interinstitucional de Cáncer Infantil," or "OICI"), with important objectives at the legislative and regulatory levels.



Awareness

81% of all foundations participated in campaigns and activities aimed at raising awareness for childhood cancer.

Colombia spearheaded the National Congress VIII and International Congress IV of Childhood Cancer for Caretakers; International Day of Childhood Cancer and awareness campaigns in schools and companies; and early childhood cancer detection, including early signs and symptoms.

In Mexico, there were campaigns and conferences directed toward the timely diagnosis of signs and symptoms of childhood cancer.

In Chile, there was support for campaigns for potential bone marrow donors, and training for early detection of childhood cancer.



Supportive Structures

During our 2018 Regional Meeting, we defined "disadvantaged countries." Based on this mapping, we identified the following countries that needed support:

- **Bolivia:** 31.7% infant mortality, 60% survive the 1st year (20% abandonment, 20% cancer, very low per capita income).
- **Ecuador:** 19% infant mortality, low public coverage 40%, 30% accredited professionals.
- **El Salvador:** high infant mortality:14.9%, low per capita income.
- **Honduras:** 7% accredited professionals.
- **Mexico:** high infant mortality 11%, 37% cancer survival.
- **Panama:** high infant mortality:11.9%, low cancer survival (34%) Fanlyc is good NGO working there.

In Bolivia, Fundación Nuestros Hijos developed a resource for Palliative Home Care (also available in Colombia, Paraguay, and Peru).

Partnerships

During the year, efforts were taken to recover partner organizations and recruit new ones which achieve the objectives. Furthermore, an Organizational Strengthening Checklist strategy was initiated: this is an instrument to identify the level of development and organization of an NGO, with the objective of defining a strengthening plan that will allow its work to be qualified. A Bolivian organization accomplished the development of this activity with the support of Elizabeth Campos, member of the Committee.



Resource Mobilization

The foundations received their funding principally through events, which in some cases represented 40%, 60% or up to 100% of their budget. Businesses also served as an important resource for funding, followed by associates and finally, the state.



Partnerships

45.5% (10) of the surveyed foundations reported that they have capacity development efforts. They organize trips to other countries to acquire and develop capacities in order to improve childhood cancer care.

Meetings that stand out: CCI LATAM 2018 (San Jose, Costa Rica), the Latin American meeting to help children with cancer.



Supportive Structures - Research

Regarding research topics, 77.3% of foundations surveyed stated that they had not carried out scientific research, except for Fundación Nuestros Hijos in Chile, which has participated in a publication of the Chilean Society of Infectious Diseases regarding immunosuppressed populations. This project investigates the standards required for the protection of oncology units from infectious diseases. Additionally, in alliance with the Ministry of Health, they are developing a study on patients' acceptance of food distributed in the Oncology Units of the Public Health Service, with the goal of changing provision strategies and quality. Another intent of this initiative is to characterize the socioeconomic profile of families of cancer patients, aiming to obtain economic benefits from the state for patients while they are in treatment. The Canica Aguascalientes Foundation in Mexico implemented an integrative model of extra-hospital pediatric psycho-oncology care.

Although these are not scientifically driven investigations, it is worth noting the work on “vigicancer” in Cali, Colombia. This is a system of epidemiologic vigilance of pediatric cancer, which highlights the importance of deepening health interventions aimed at impacting epidemiological surveillance systems. This allows for the identification and registration of cases, the systemization and analysis of information and the dissemination of records in the pediatric oncology population.

At this time, according to what was established in our last LATAM meeting, we are initiating a collaborative observational study in LATAM in order to answer the following question: What knowledge do childhood cancer survivors in Latin America have about their diagnosis and possible late effects? Our objective is to use these results to empower and educate survivors to aim for a better passage to adulthood and enforce the necessary self-care to improve their health and avoid future illnesses.

Regional LATAM Conference

Between the 30th of May and the 1st of June, the XI conference was held in San José City, Costa Rica. Sixteen organizations from nine different countries participated. The commitments and tasks at a regional level included the following:

Promote Membership Regularizations and Invite New Members into the Network

To facilitate the communication and relationship between new foundations, a representative was chosen per country to contact the member Foundations who are delayed in their payments and to research new foundations that want to be part of the CCI Region.



Definition of Tasks in the Region

Based on the presented mapping, the following topics were defined as priorities to improve survival in the region:

- Improve access to medicines;
- Avoid abandonment: psychosocial work, support in mobilization, food, psychological, school, entertainment, shelter, home repair;
- Improve infrastructure and equipment;
- Complement in the medical area the shortcomings of the system, including:
 - Diagnostics
 - Treatments
 - Follow up
 - Nutrition
 - Palliative Care
 - Rehabilitation
 - Follow up



Acting as an Organization

As a Latin American Network, we share tasks and actions so we can develop them together, such as:

- Global Impact, International campaigns, Children's Cancer Day, Survivor's Day, Golden September
- National Impact: Promoting the suggested actions, aim at an impact on public policies
- Raising awareness
- Promoting investigation
- As an institution, focus specifically and primarily on:
 - Diminishing abandonment
 - Hospital schools
 - Teenage problems
 - Survivors
 - License for the caretaker
 - Palliative care

Tasks related to educational material recollection from the foundations to contribute to the ICC Knowledge Portal

We collected material that can be useful to strengthen strategic topics or those susceptible to be shared through the website.

Tasks Related to Palliative Care

Based on the Mapping, the following support needs were identified:

- Country's law on palliative care that covers children with cancer;
- Percentage of children who die at home;
- Problems with the handling of palliative care.





African Regional Committee (ARC) Established



Organisationally and structurally, it was a good year for CCI Africa. The region’s leaders came together, a formal regional committee was appointed, and good work has been done in collaborations and advancing the cause of childhood cancer in Africa.

In May, on behalf of Childhood Cancer international (CCI), ACCO (American Childhood Cancer Organization) and CHOC hosted a very successful CCI Africa Strategy Workshop in Johannesburg. During the workshop, we elected a new CCI ARC (Africa Regional committee) whose members are:

- Carl Queiros (of CHOC, South Africa)*
- Daniel McKenzie (of Kidzcan Children Cancer Relief Organisation, Zimbabwe)*
- Brain Walusimbi (of Bless a Child Foundation, Uganda)*
- Prof Yasser Sadek (of Alexandria Group of Childhood Cancer Care (AGCCC))*
- Dr Ihesinachi Kalagbor (of Simara Children Cancer Foundation (SCCaF) Nigeria)*
- Dr John Ahenkorah (of Ghana Parents Association for Childhood Cancer (GHAPACC) Ghana)*
- Sidney Chahonyo (of Hope for Cancer Kids (HCK)).*

We set up three Task Teams (TTs) with representatives from several countries.



Advocacy & Awareness



Resource Mobilization



Palliative & Supportive Care

The year’s work of the ARC was initially focused on building and organising itself, and later on assisting the SIOP Africa (Egypt) LOC (local organising committee) in the planning and preparing for the parent and patient track of the SIOP - CCI Africa Conference, May 2019.

Communications and Branding

The ARC has recognised that CCI Africa and the CCI brand are not well known in Africa, particularly among donors, corporates, and the public. It was agreed that we should use every opportunity to promote the CCI Africa brand and logo.



Some good developments occurred in 2018 in this regard, with some of the successes being:

- 1. Many of the members began including the CCI Africa logo in their communications and social media, and connecting with global CCI campaigns.*
- 2. We developed an organisational profile.*
- 3. We produced branding material such as banners, a signature panel, a letterhead, and t-shirts.*
- 4. We began seeing news about CCI Africa and our members featured more on the communications of our partners and networks, as well as in the general media.*

Zambia

Awareness

The Kayula Childhood Cancer Foundation's (KCCF) awareness and fundraising events included a football tournament and a running race. The Football Tournament was held in September and corporate teams competed with each other and paid an entry fee to participate.

PWC's Race to Beat Cancer raised awareness and funding for KCCF. 542 runners took part in the race.



Ghana

Supportive Structures

GHAPACC received a significant donation from the First Lady to continue with their housing project. They have now started with construction on the third floor.



Photo: Dr John Ahenkorah and Kwame Aveh, Chairman, inspecting the building

Zimbabwe

Supportive Structures

Kidzcan Zimbabwe Retinoblastoma and Wilms Tumour, in collaboration with the Ministry of Health and Child Care, ran an Early Detection Campaign to promote early diagnosis and improve treatment outcomes and quality of life for children suffering from Retinoblastoma and Wilms Tumour in Harare and Chitungwiza. The campaign which is funded by UNICEF is expected to bring the following results:

1. Improved knowledge of screening for Wilms Tumour and Retinoblastoma among health practitioners in Harare and Chitungwiza.
2. Increased awareness on Childhood Cancers among the communities and general health workers in Chitungwiza and Harare.
3. Empowered communities with information about Wilms Tumour and Retinoblastoma demanding to have their children screened for cancer.

The campaign started with the training of 430 community health workers who will mobilise communities to take their children for screening, and medical staff who will screen children coming to the baby clinic. A cancer diagnosis card will then be attached to the vaccination card.

Kenya

Awareness

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 the Nairobi city center.



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.

Rwanda

Awareness

The Rwanda Children's Cancer Relief (RCCR) carried out a number of awareness raising activities including: a World Cancer Day celebration, hospital visits, participation in meetings and conferences, a Kid's Cancer Walk, and awareness interviews and talks on the media (printed and live). In addition, RCCR expanded its awareness education and capacity building for health centres and community health workers. More than 140 health centres' staff and community health workers were trained on childhood cancers and the campaign reached over 1,000 people, care providers from 4 health centres, and 50 community health workers.

Ethiopia

Partnerships

Mathiwos Wondu-Ye Ethiopia Cancer Society (MWECS), with financial & technical support from the American Academy of Paediatrics/NCD Child and with the leadership of FMOH, participation from five regional universities, key participants from CSOs, Professionals Associations, FMOH ,Academia and Research Institutions developed a draft National Childhood & Adolescent Cancer Control Plan of Ethiopia. This was submitted to the executive committee of the Federal Ministry of Health (FMOH) for approval.

The Childhood and Adolescent Cancer Control Plan of Ethiopia was finally reviewed and approved by the FMOH and will be launched very soon.



Some of the participants of the first and second Childhood and Adolescent Cancer Consultative meetings posed for the photos.

South Africa

Supportive Structures

CHOC (Childhood Cancer Foundation's programme) funds and supports the national childhood cancer registry (the SACTR). Since 2008, the SACTR reported over 1,000 new cases for the first time in 10 years where previously it recorded between 600-800 cases annually. It is estimated that as many cases go undiagnosed.

In 2011, CHOC started with an Awareness Program. We trained healthcare professionals, healthcare workers, traditional healers and NGOs on the early warning signs of childhood cancer. From 2011 to the end of 2018, 25,358 individuals have been trained during 567 sessions.

Awareness

In 2018, CHOC had 8 national television broadcasts; 23 radio broadcasts, appeared 47 times in national and local newspapers, and had 44 online news clips appearances.

The Heart for Children with Cancer Campaign commemorated International Childhood Cancer Day (ICCD) this year. CHOC once again called on companies, schools and individuals to "go blue" by purchasing their CHOC pins, badges and chocolates.

CHOC was honoured to be selected as a charity of choice of the world's oldest and largest ultra-marathon, the Comrades Marathon.

Childhood Cancer Awareness Month (September). During the month of September 2018, CHOC hosted a number of events and social media campaigns to raise public awareness of childhood cancer. Pay-it-forward teas were held throughout the country and gold merchandise like satin ribbons, beaded ribbons, nail varnish, and bags were sold.

Resource Mobilization

This year marked 100 years since the birth of Nelson Mandela, and in celebrating his centenary, CHOC provided nationwide support for the CHOC families. Mandela Day participants were encouraged to change the world for the better by donating items from regional wish lists.

Clover Nutrikids Partnership. Clover and CHOC joined forces to raise sufficient funds to purchase a new Nutrikids CHOC House in Pretoria. Initiatives included telethons on Expresso TV.

Uganda

Supportive Structures

Bless a Child Foundation (BCF) provided psychosocial support services to 269 children and their caregivers at the BCF Kampala and Gulu homes. 236 children received subsidized treatment support. The organisation supported 20 children to continue with their education after treatment and provided remedial classes to 194 children at the BCF home schools.



BCF provided internship placements for 10 students from various universities.



Partnerships

BCF had several collaborations with new partners coming on board during 2018. Four successful fundraising campaigns were held. BCF participated in the World Cancer Day 2018 celebrations that were held at the Uganda Parliament.

Brian Walusimbi, the Executive Director was presented with the 66th Points of Light award from Her Majesty the Queen of England in recognition for his exceptional service supporting critically ill children.

Some of the challenges for the organization were:

- 25 children died from cancer in the year 2018;
- Stock-outs of essential drugs at the UCI and Lacor hospital;
- Radiotherapy treatment is not free any more;
- Limited accommodation space;
- Funds; expenditure exceeded our income by 6.9%;

We learned that we need to tackle more cancer awareness and support services across the country, as cancer treatment continues to be a challenge for most families in Uganda.

Nigeria

Awareness

Simara Children Cancer Foundation's (SCCaF) awareness campaign and cancer education is one activity they carry out every year and 2018 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 was able to increase the number of parents who brought their children to the hospital when some of the warning signs were noticed. SCCaF donated one hundred thousand naira (N100,000) every quarter to the Indigent Funds for Cancer Children in the University of Port Harcourt Teaching Hospital (UPTH).



ICCD celebration (5th year) was celebrated with a lecture in collaboration with Drop Cancer organization. SCCaF donated the sum of one hundred thousand naira (N 100,000) into the Indigent Fund to assist in providing drugs and medical care for the children.

Children Living With Cancer Foundation (CLWCF) started off 2018 with the annual ICCD, spanning two weeks. CLWCF celebrated ICCD day at an Art competition and exhibition held in Lagos.



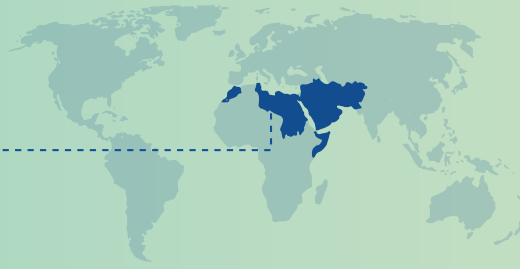
Had a sitout/town hall meeting with students from different schools, heads of Industries and a representative of the Health ministry in Lagos.

In May, for children's day period, lectures, seminars were given at schools to create childhood cancer awareness.

In September, CLWCF released gold coloured balloons across Nigeria, in different states and cities on the first of September. Other activities carried out for the month of September included: lecturers at different markets, organizations, and malls, an art exhibition at the National theatre, Lagos, and for the first time, a stage production on childhood cancers! All to mark the childhood cancer awareness month, September.

In December, a Christmas party was held at the Children oncology ward LUTH. Awareness for childhood cancers and the need to give them hope was created before the party. Gift items were distributed to the children, friends, families and caregivers, and the ward.





Syria

Supportive Structures

During 2018, due to the increasing intensity of the military crisis in Damascus suburb, BASMA association had a great challenge to survive and keep the function of one of its most important program—BASMA Pediatrics Oncology Unit—running. After standing in the battle area for five years, the unit was completely unsafe for patients and staff. On 25 February, 2018, we managed to secure a safer place a few kilometers away. The patients were transferred with IV chemotherapy running. No casualties happened. A few months later, the unit returned to its permanent location after the military operations were over.



UAE

Supportive Structures

‘Joy Cart’ is a moral support initiative by Friends of Cancer Patients (FoCP) that not only brings smiles to children who are bravely battling cancer, but has the longterm effect of instilling normalcy in their lives by engaging them in creative activities. FoCP’s ‘Joy Cart’ initiative has been making rounds at pediatric cancer wards across UAE, spreading happiness and hope in the lives of young patients fighting this difficult disease.

Iraq

Supportive Structures

Kurdistan Save the Children (KSC) provided seven accomodations, sent twenty-five children to MAHAK, Iran, for further treatment, and reintegrated children back into their routine after treatment.

**Iran
MAHAK**

Partnerships

MAHAK signed an MOU with two charities in Isfahan and Khorasan state, according to which the children have access to services provided by MAHAK, paid on-site costs, and continued practices for supporting cancer patients. This developed capacity building and accelerated the process of providing comprehensive and integrated treatment and support services to children with cancer throughout the country, so that no child with cancer would be deprived from treatment due to poverty and lack of facilities.



Opening MAHAK’s HLA typing bank with 5000 primary donated samples was a one-year-project that aimed to facilitate treatment, not only for children with cancer and their families, but also for all patients in need of transplantation in Iran and neighboring countries.

Morocco

🏠 *Supportive Structures*

The Association l'Avenir signed a convention with the ministry of Education which allowed the association to create a school and a multimedia room at the “House of l'Avenir.” A teacher is permanently there to cover several activities such as teaching, art activities, and workshops. The school provides opportunities to develop social skills and gain knowledge needed for a successful future, and keeps children with cancer focused on positive aspects of their life and future.



Egypt

💰 *Resource Mobilization*

Alexandria Group of Childhood Cancer Care’s (AGCCC) fundraising campaign had been organized in Alexandria Sporting Club led by some parents, charity people, volunteers, and rotary members of Alexandria Rotary Club.

There were renovations of out-patient clinics within the compound of the Hospitality House for Caring of Cancer Children for the first aid medical services for cancer children during their accommodation in the house.

Azerbaijan

🎗️ *Awareness - ICCD 2018*

Celebrities Against Leukemia is a project launched by Charter of “Fighting Leukemia” Public Union. The main goal of this project was to ensure the state’s authorities were able to see the problem in Azerbaijan and do anything they could to prevent children dying from leukemia. The project also aimed to make public awareness of the disease so more people will help children fight against leukemia. The project has been well supported by famous singers.



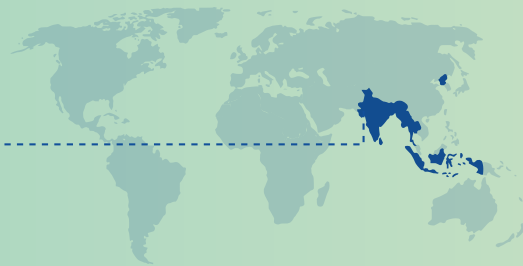
Lebanon

🎗️ *Awareness*

Early diagnosis saves lives. CHANCE (CHildren AgaiNst CancEr) Association launched a nationwide campaign in several schools entitled *Ribbons of Hope* to educate parents on the early warning signs of childhood cancer.



Children’s Cancer Center of Lebanon (CCCL) established a club for all the triumphant survivors of this horrible disease, and we called it the Champions’ Circle! The Champions’ Circle meets once a month for activities such as Psychosocial Support sessions, Positive Thinking trainings, Yoga and Healing, and more.



India

Supportive Structures

On ICCD 2018, Eeshwar Child Welfare Foundation (ECWF) organized an event for the underprivileged childhood cancer patients, providing lively music, dance and games. Gifts and pastries were distributed among their warriors. It was deeply satisfying to watch the kids ignore their ailments and enjoy the event to the fullest.



Awareness

A support group of childhood cancer survivors was established under the survivorship program of the Indian Cancer Society. UGAM aims to help survivors become the ambassador of the message “*Childhood Cancer is Curable.*” Among various awareness activities organized by UGAM, one of the most successful was a cricket match on World Cancer Day.

Partnerships

Cankids...KidsCan signed MOUs with two state governments (Punjab and Maharashtra) as their knowledge and technical partners for childhood cancer. Their new vCAN (virtual Cankids Assistance Network) registered 8700 patient families supported with over 56,844 episodes of assistance provided.



Bangladesh

Supportive Structures

ASHIC Foundation for Childhood Cancer established another shelter in Dhaka on 20 May, 2018, in their own property in a fourteen-story commercial and residential building. The shelter consists of two apartments: one is 1953 sq.ft. and the other is 1686 sq.ft. with a total of 3639 sq.ft. joined together to make a single facility of twenty beds.

Myanmar

Awareness - ICCD 2018

The very first celebration of ICCD in Mandalay, Myanmar was held on 24 February, 2018. From Mandalay Children’s Hospital and Mandalay General Hospital, the children with cancer and their families had the chance to enjoy the event locally with the heartfelt support of passionate caregivers, student volunteers, teachers, and multi-stakeholders. The event kicked off in Ayeyarwaddy International School (AIS).



Indonesia

Awareness

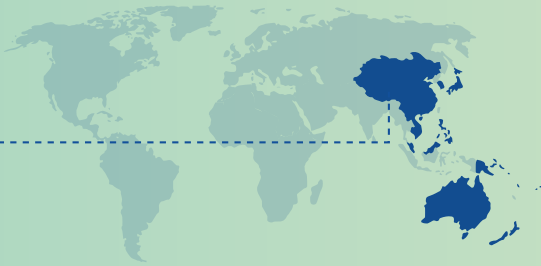
In celebration of the 25th anniversary, YOAI held a musical performance called "Rasa, Caring from the Heart." Through the drama, YOAI spread the message that children with cancer can be cured, provided they come at early stages. This activity also spread the spirit and positive message to patients of children with cancer that recovery is not an impossible thing to achieve.



Resource Mobilization

Indonesian Childhood Cancer Foundation (YOAI) set up a teenagers ward at Dharmais Cancer Hospital, the National Cancer Center for another 1,000 sqm. with 42 beds, as an extension of the children ward that was set up in 2005. YOAI accepted a grant from Prudential Life Assurance Indonesia to set up the Teenagers Ward which is the first Teenagers Ward in Indonesia.

Yayasan Anyo Indonesia (YAI) donated 677 units of ophthalmoscopes to 22 provinces under the 1,000 ophthalmoscope movement program. The purpose of the 1,000 ophthalmoscope movement program is not only to save the children's lives but also to save their eyes and vision.



South Korea

Awareness

The Korean Association for Children with Leukemia and Cancer (KACLC) provided a program, *An Educational Visit for Understanding Childhood Cancer*, which supports childhood cancer survivors to return to their school community and helps peers to better understand childhood cancer.



An exhibition and campaign on childhood cancer awareness was held at Citizen Gallery, Seoul Citizen Hall. One of the activities was putting together the pieces of a puzzle with hopeful messages for children with cancer. Some children who were playing and solving the quizzes said “We’ll be nice to children with cancer and be their good friends if we meet them at school.”

China

Awareness - ICCD 2018

The annual Charity Walk of PKW (Pau Kwong Wun Charitable Foundation) has become an iconic event of ICCD, bringing together the community with enthusiastic student volunteers, energetic childhood cancer survivors, education professionals, and medical teams from Hong Kong and China. All participants shared the same vision of a better world, without leaving children with cancer and their families behind.



Malaysia

Supportive Structures

One of NCSM’s (National Cancer Society of Malaysia) major achievements and successes this year was the introduction of a play therapist for children with cancer. The actual play therapy had been going for almost twelve months, but in September of 2018 they employed a full time play therapist to cover Kuala Lumpur and Melaka.

Viet Nam

Supportive Structures

In 2018, ICCD occurred during Lunar New Year in Vietnam. Therefore, all children wore colorful aodai (traditional dress in Vietnam) for photo taking. In the evening, CCFGCV (Childhood Cancer Family Group in Central Vietnam) held a party with cakes and candies for children and their parents. They felt very happy because they have not overcome this journey alone.



Partnerships

Asian Children’s Care League (ACCL), Japan, has been carrying out the childhood cancer project in Vietnam since 2005, and they are very pleased that Hue Central Hospital-Pediatric Center’s new floor for highly specialized treatment and care of oncology-hematology diseases was opened in December, 2018.





CCI-Europe Regional Committee (ERC)

After three additional members of the CCI-EReC (Childhood Cancer International – Europe Regional Committee) joined in 2017, 2018 was the year in which working procedures were outlined and working groups formed. A highlight was the input from CCI-Europe member organisations regarding the needs of national organisations during the CCI-Europe Regional Committee. This discussion formed the further development of CCI-Europe.

The position of CCI-Europe within the region and within the paediatric oncology community was strengthened through closer collaboration with SIOP-Europe and PanCare. These collaborations are leading to a robust voice for patients and their families and for survivors of childhood cancer within Europe.



Advocacy

Important steps to promote the rights of European paediatric patients and parents were made through various discussions with policy makers at the European Parliament. At the International Childhood Cancer Awareness Day Event, CCI-Europe, together with SIOP-Europe, made a strong case that the next EU budget for research and health should include paediatric cancer as a priority. Jaap den Hartogh and Aida Kopriva-Kryeziu (CCI-Europe Survivors Network) emphasised on the need of adequate follow-up care. Lejla Kameric (CCI-EU steering committee member) stressed further the crucial role of patients, parents and survivors and their involvement in EU projects.



During the childhood cancer awareness month in September, 20 years' progress in paediatric haemato-oncology in Europe was celebrated through the MAC (MEPs Against Cancer) Event at the European Parliament. Holly Watwil (CCI-EU steering committee member) and Aida Kopriva-Kryeziu (European Survivors Network) did an excellent job in representing the patients/survivors' perspective and informing politicians about the current needs of this population in Europe. The event was rounded up with the evenings SIOP Europe Gold Ribbon award. CCI-Europe was one, who obtained the Gold Ribbon Award for its outstanding effort to making a difference in the paediatric cancer cause.

Awareness

Next to the Childhood Cancer International Campaign **#nomorecomplacency**, focusing on raising awareness to reduce inequalities in cure rates around the globe, CCI-Europe started an awareness campaign for childhood cancer as identified as high priority in Europe. CCI-Europe members were encouraged to get a “GOLD RIBBON TATTOO,” take pictures with it, and most importantly share it on social media with the Hashtag **#gold4KidswithCancer**. Our members were very well engaged and participated euphorically. Also, the survivors community (pictured below) was actively engaged. Through this campaign, we were able to reach more individuals and spread the word to fight childhood cancer across Europe.



Supportive Structures

The 9th CCI-Europe Regional Conference took place from 13 – 15 April 2018. 115 participants from 24 countries attended the event which was hosted by the Portuguese member organisation - ACREDITAR in Lisbon (Portugal). The main theme of the conference - Fit for the future - was clearly visible through hot topics including: precision medicine, immunotherapy, follow-up care for survivors, educational opportunities, and how to grow local parents and patients’ organisations.

For the first time, a unique discourse for discussion was presented by various stakeholders, the medical field (including experts in paediatric oncology and new therapies), the industry (Shire), SIOP-Europe, and new parents and patients’ organisations. It was an eye-opener for the medical community as well as for CCI-Europe to enhance collaboration across the disciplines and include parents/patients and survivors in the full range of the decision-making processes.

A Unique Twinning Programme in Sumy

For the last twenty years, the Austrian childhood cancer organization has had a twinning program with the childhood cancer organization in Sumy (Ukraine), VIDEN. Thanks to this financial support, essential drugs for childhood cancer patients was obtained. Through a pharmacy contract the organisation was able to order and buy the medicines needed, which they provided to the hospital. Moreover, through this excellent support, a psychologist, which was so badly needed for the children and their families, was employed. At the end of May 2018, a new ward for paediatric oncology in Sumy was opened, comparable with other hospitals in that area. The renovation took nearly ten years and was only possible because of collaborations with various organisations. The main support for the renovation came from the Caritas association for the diocese Trier and the Antonia-Ruut-Stiftung Trier.

Resource Mobilization

The finance and resource mobilisation working group was able to establish a “funding document,” outlining various activities of CCI-Europe which will be used to contact companies interested in supporting CCI-Europe. During the finance working group meeting in July it was agreed to ask pharma companies, companies for children’s products, health related sports companies as well as other European companies for financial support. Furthermore, in 2018, it acquired a cooperation with Shire, who is supporting CCI-Europe on an annual basis in capacity building and education.

Supportive Structures - Research

ERN PaedCan (European Reference Network in Paediatric Oncology)

With the official start of the 24 European Reference Networks in March 2017, the European Commission initiated one of the most relevant projects for the care of patients suffering from a rare disease in Europe. One of the 24 established networks is dealing with Paediatric Cancer (ERN PaedCan). The aim of the ERN PaedCan is the facilitation of knowledge across borders through the development of a clinical patient management system (online consultation system, connecting European hospitals) and the enhancement of treatment and care of all childhood cancer patients in Europe no matter where they live. The ERN PaedCan comprises 57 hospitals which are all interconnected to help patients obtain access to the care they need. CCI-Europe is involved in the Steering Committee of the network and hence included in the decision making.

Part of Oversight Committee of ERN PaedCan



One activity of CCI-Europe is the identification of national points of contact in each country, to which childhood cancer patients and their families can turn to when referred to a different country, or when a second opinion is needed. CCI-Europe has an intermediary role in passing on information to parents from the ERN PaedCan Coordinator and vice versa. In 2018, the overall requirements of a National Contact Point were defined and already 24 contact points were identified. During a very productive workshop at the 9th CCI Regional Conference in April, differences and necessities in various European countries were discussed with members. The structure is outlined in the graph above.

JARC (Joint Action on Rare Cancers)

CCI Europe is deeply involved in the Joint Action on Rare Cancers (JARC), especially in Work Package 9 dealing with Childhood Cancers, led by SIOP-Europe. CCI-Europe Steering Committee members are included in the paediatric radiotherapy Working Group. In 2018, CCI-Europe was involved in the development of a “Rare Cancers Policy,” to increase the adoption of concrete national measures to improve the offer for care and follow-up.

Furthermore, CCI-Europe and responsible individuals from JARC created a European survey on essential medicines for paediatric malignancies. To understand the potential gaps of knowledge within the rare cancer community (including adult cancers), CCI-Europe, the European Cancer Patient Coalition (ECPC) and EURORDIS sent out an additional questionnaire.

WECAN (Workgroup of European Cancer Patient Advocacy Networks)

WECAN provides next to the knowledge exchange and joint projects, the opportunity for our members to obtain knowledge through trainings courses. In 2018, 3 members and the CCI-Europe project manager participated at a trainings course of the Workgroup giving different insights on patient advocacy.

Harmony (Healthcare Alliance for Resourceful Medicine Offensive against Neoplasms in Hematology)

Harmony is a public-private network which uses the benefits of big data to speed up the development of improved treatments for patients and more effective treatment strategies. CCI-Europe is actively involved in representing patients’ rights and voicing the interest of the patients across all activities of the network.

Accelerate (Innovation for Children and Adolescents with Cancer)

One CCI-Europe Steering Group member, Nicole Scobie is included in the Accelerate Platform, which is focused on the process of speeding up the evaluation of innovative therapies and introducing them in the standard cancer care in children and adolescents.

Partnerships

Throughout 2018, additional members requested to join the network and were approved by CCI in Kyoto. These included: Karkinaki Organisation (Greece), Onssteentje (Belgium), Imagine for Margo (France) and Monk Andrew's Foundation (Georgia).

The Head of CCI-Europe and some steering committee members met with the Swedish member organisation Barncancerfonden in August. The goal of the meeting was to obtain more information from both sides on activities and foster closer collaboration in the future.

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

PanCare is actively working to set up follow-up structures for childhood cancer survivors. One survivor of CCI-Europe is also involved in the Board of PanCare. Furthermore, a new EU project was submitted by PanCare (PanCareFollowUp) placing CCI-Europe in a central partner role.

SIOP Europe (European Society in Paediatric Oncology)

Collaboration with SIOP-Europe is crucial in various aspects from research to prioritisation. Since 2018 it was agreed that SIOP-Europe and CCI-Europe would focus more strongly on EU policy.

EURORDIS (Rare Disease Europe)

EURORDIS has established European Advocacy Groups (ePAGs) within all 24 European Reference Networks (ERNs). Their focus in 2018 was mainly on linking these ePAGs and fostering cooperation through creating an ePAG steering committee which met the first time 13-14 September 2018. CCI-Europe and EURORDIS established a very good working relationship in the past year.

ECCO (European Cancer Organisation)

The head of the CCI-Europe Regional Committee is included in the ECCO patient group. Hence, permanent exchange of knowledge and collaboration is given between the adult and the paediatric cancer community.

CCI ESN (CCI Europe Survivors Network)

This network met in the newly built Princess Maxima Cancer Centre in Utrecht from 23-25 November, discussing needs of survivors in various countries.

It is through the work of Childhood Cancer International, its members, and its partners that we are able to make the world a better place for children with cancer and their families. We look forward to 2019 and continuing the great work together.



*“We can change
the world and make it a better
place. It is in our hands to make a
difference.”*

- Nelson Mandela



Childhood Cancer International

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

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