



# CCI 2017 ANNUAL REPORT

**BETTER CARE FOR A BETTER LIFE**



# A LETTER FROM THE PRESIDENT

Dear CCI Colleagues,

As we start a new year we must look back upon the year that has just passed. For many of us, 2017 was filled with sadness and the loss of too many children who were gone too soon. More than 300,000 children around the world faced a childhood cancer diagnosis and too many of them had little hope for a cure. Some of these were our own children; some were children whom we served through our organizations. My hope is that time will bring healing and as former U.S. Vice President Joe Biden said, "There will come a day when the thought of your son or daughter (or your husband or wife) brings a smile to your lips before it brings a tear to your eye."

2017 was also filled with the knowledge that as individuals, member organizations and together as CCI, we continued to serve children and adolescents with cancer and their families around the world. We raised awareness, increased access to care, staffed treatment centers, advocated to the highest levels of government regionally, nationally and internationally, created coalitions with other key stakeholders and provided support to hundreds of thousands of children fighting this disease, survivors and their families. Together, we grew to become the largest childhood cancer grassroots organization in the world with a global network of 188 member organizations in 96 countries all strongly committed to "Advancing Cure & Transforming Care." On behalf of the CCI Board of Trustees I want to thank each and every one of you for your commitment to our common vision that children and adolescents with cancer benefit from the best possible treatment, care and support wherever they live in the world.

As 2018 begins, we must also look forward to the year ahead. A new year brings the opportunities to dream and to take more steps towards the goals that will help to further this cause that is so dear to each of our lives. It is a time to start where we are, use what we have and do what we can.

- One opportunity to Build Awareness and Mobilize Support is through supporting CCI Signature Events including International Childhood Cancer Day (ICCD), which is held February 15th each year. (<http://www.internationalchildhoodcancerday.org>). We encourage all member organizations and childhood cancer stakeholders to participate on Feb. 15th 2018 to highlight the need for concerted local and global actions to address the growing challenges posed by childhood cancer.
- Another opportunity is to engage in collaborative initiatives with other CCI members and regional committees.
- We encourage you to take the opportunity to share expertise and learn from others through participation in CCI regional conferences as well as to plan ahead to attend the annual Congress which will take place in Kyoto, Japan Nov. 16-19th, 2018 (<http://siop-online.org/event/siop-2018/>)
- The CCI Board also encourages members to share your program successes via our newsletter and social media by sending summaries and pictures to: [headoffice@cci.care](mailto:headoffice@cci.care) The CCI Board of Trustees is volunteers. Many do this in addition to leading CCI member organizations as well as their own careers. I couldn't be more proud to introduce the following 2018 Board of Trustees as approved at the AGA, October 14, 2017 in Washington DC.

NAME	REGION	ROLE
Ruth Hoffman	United States of America	President
Carmen Auste	Philippines	Immediate Past
Luisa Basset	Spain	Secretary
João Bragança	Portugal	Treasurer
Marcela Zubieta	Chile	Member
Mary MacCowan	Australia	Member
Nicole Scobie	Switzerland	Member

On behalf of the Board of Trustees and myself, I wish all of you the best in 2018 as we work together to Advance Cure and Transform Care for children and adolescents with cancer.



**Ruth Hoffman MPH,**  
*President,*

**CHILDHOOD CANCER  
INTERNATIONAL**



# BOARD OF TRUSTEES



## Carmen Auste

### Chair

Carmen is mother of James, a teen brain cancer survivor who founded Cancer Warriors Foundation. She is the Managing Director of CWFI and an international development consultant for the United Nations system and major development partners (i.e., AUSAID, USAID, GIZ, JICA, Millennium Challenge Corporation). Carmen is a social psychologist by profession and has worked in the public policy and program arena for the past 35 years.



## Ruth Hoffman

### Vice-Chair

Ruth is the mother of eight children, including 36-year old Naomi, a 29 year survivor of AML. Ruth is the Executive Director of the American Childhood Cancer Organization and is an author/ editor of 11 childhood cancer learning resources. She has a Masters in Public Health.



## Luisa Basset

### Secretary

Luisa is mother of Victor, a survivor of a mature B-cell ALL diagnosed in 1990. She is involved at local, national and international levels, representing Federacion Espanola de Padres de Ninos con Cancer and is a Professor at the School of Architecture in Valencia



## Poonam Bagai

### Treasurer

Poonam is the mother of 2 boys who were 7 and 3 when she was diagnosed with colon cancer. She founded Cankids Kiscan, which has supported over 17,000 families of children with cancer to date through its numerous programs.



## Marcela Zubieta

### Member

Marcela is a pediatrician who lost her 3 year old daughter to a brain tumor (Chronic Plexus Carcinoma). The tragic experience made her refocus her professional social life to serve under privileged children with cancer living in Chile.



## Kenneth Dolman

### Member

Kenneth is the father of Jennah, who survived cancer as a 20-month old toddler in 1995. He is a founding member of CHOC Childhood Cancer Foundation South Africa and is passionate about establishing support groups across Africa.



## Joao Maria De Lencarte

### Member

Joao lost his 7 year old daughter Madalena to a brain tumor. He is President of the Portuguese Association of Children with Cancer. He is a mechanical engineer who translates patents and books from renowned publishers to Portuguese.



## Mary McGowan

### Member

Mary is a registered nurse with over 30 years' experience in pediatric oncology. She is the Community Liaison Manager of the Children's Cancer Centre at the Royal Children's Hospital Melbourne Australia, and facilitator of the Parent Advisory Group of the Cancer Centre.



## Kwame Aveh

### Member

Kwame is the bereaved father of the late master Elorm Aveh, who died of leukemia at age 9. Kwame is the Chairman of the Ghana Parents Association for Childhood Cancers (GHAPACC). He is a Chartered Accountant and Development Finance Specialist as well as the Head of Department at the Ghana institute of management and Public Administration.



# INCOMING BOARD OF TRUSTEES for 2018



**Ruth Isabella Hoffman**  
**MPH**

**President**

Ruth is the mother of eight children, including 36 year old Naomi, a 29 year survivor of AML. Ruth is the Executive Director of the American Childhood Cancer Organization and is author/ editor of 11 childhood cancer learning resources



**Carmen Auste**  
**Immediate Past President/  
Vice President**

Carmen is mother of James, a teen brain cancer survivor who founded Cancer Warriors Fnd. She is the Managing Director of CWFI and an international development consultant for the United Nations system and major development partners (i.e., AUSAID, USAID, GIZ, JICA, Millennium Challenge).



**Luisa Basset**

**Secretary**

Luisa is mother of Victor, a survivor of a mature B-cell ALL diagnosed in 1990. She is involved at local, national and international levels, representing "Federación Española de Padres de Niños con Cáncer" and is a Professor at the School of Architecture in Valencia.



**Joao Maria De Lencastre  
De Braganza**

**Treasurer**

João lost his 7 year old daughter Madalena to a brain tumour. He is President of the Portuguese Association of Children with Cancer. He is a mechanical engineer who translates patents and books from renowned publishers to Portuguese.

CCI'S LEADERSHIP  
TEAM VOLUNTEER THEIR  
TIME TO TRANSFORM THE  
CARE AND QUALITY OF LIFE  
OF CHILDREN WITH  
CANCER, SURVIVORS AND  
THEIR FAMILIES.



**Nicole Scobie**

**Member**

Nicole is the mother of three boys, one of whom is a survivor of childhood cancer. She is the president of Zoe4life, a non-profit organization based in Switzerland which supports kids with cancer and their families, funds and advocates for research. She is also on the Accelerate platform steering committee.



**Marcela Zubieta Acuna**

**Member**

Marcela is a pediatrician who lost her 3 year old daughter to a brain tumor (Choroid Plexus Carcinoma). The tragic experience made her refocus her professional and social life to serve underprivileged children with cancer living in Chile.



**Mary McGowan**

**Member**

Mary is a registered nurse with over 30 years' experience in pediatric oncology. She is the Community Liaison Manager of the Children's Cancer Centre at the Royal Children's Hospital Melbourne, Australia, and facilitator of the Parent Advisory Group of the Cancer Centre.



# CCI GLOBAL NETWORK

Below you can find a world map divided into regions.

Currently Childhood Cancer International represents 188 childhood cancer parent organisations in 96 countries



## MEMBERS 2017

	REGION	COUNTRIES	ORGANIZATIONS
●	Asia	23	48
●	Africa	16	24
●	Europe	34	70
●	Latin America	18	36
●	North America	2	6
●	Oceania	3	4
	<b>TOTAL</b>	<b>96</b>	<b>188</b>



# CHILDHOOD CANCER INTERNATIONAL OCEANIA: Working Together Works

## A. Cross Country Collaboration and Support for Enhancing Capacities in Childhood Cancer Care of Small Island Developing Countries

### NEW ZEALAND

CCI and its collaborating partner, the World Child Charitable Trust New Zealand, has continued to work closely with the Government of Fiji and have signed off on an MOU which will include providing funds for hiring an Outreach Paediatric Oncology Nurse.

They also continue to support and work closely with the Ministries of Health in the small island developing countries of Tonga, Vanuatu, and Samoa. They provide childhood cancer education and training for both health staff and families with the aim to improve childhood cancer literacy and survivorship outcomes.

### AUSTRALIA

CCI member, The Royal Childrens Hospital (RCH) in Melbourne, continued the weekly teleconference meetings between their medical and nursing staff and the staff in Papua New Guinea. There is a plan to have a parent link up in the not too distant future .

A nurse and doctor from RCH- Melbourne also held a workshop in Dili, East Timor for the staff from 2 different hospitals in the city and continue to provide on line coaching, as needed. Upon the return from Laos, of a junior medical staff who spent one year working with the staff there, a doctor from Laos was sent on a three month secondment to RCH.



MY ROOM a Philanthropic group based in Melbourne funded chemotherapy for two patients in East Timor. It also enabled two parents and survivors from Indonesia and India to attend the annual Childhood Cancer conference in Washington D.C



## B. High Impact Social Mobilization and Community Awareness Raising for Childhood Cancer

### NEW ZEALAND

The Children's Cancer Foundation New Zealand in conjunction with Wild in Art had a high impact , highly visible awareness campaign with Hoot for Owls in March throughout the streets of Auckland.

This follows their highly successful fund raising event, Wig Wednesday, first launched in 2016 to businesses and schools, with a license agreement from Clic Sargent UK.

Over 214 schools and businesses participated throughout New Zealand and over 3.5 million people were reached with our PR and media content.

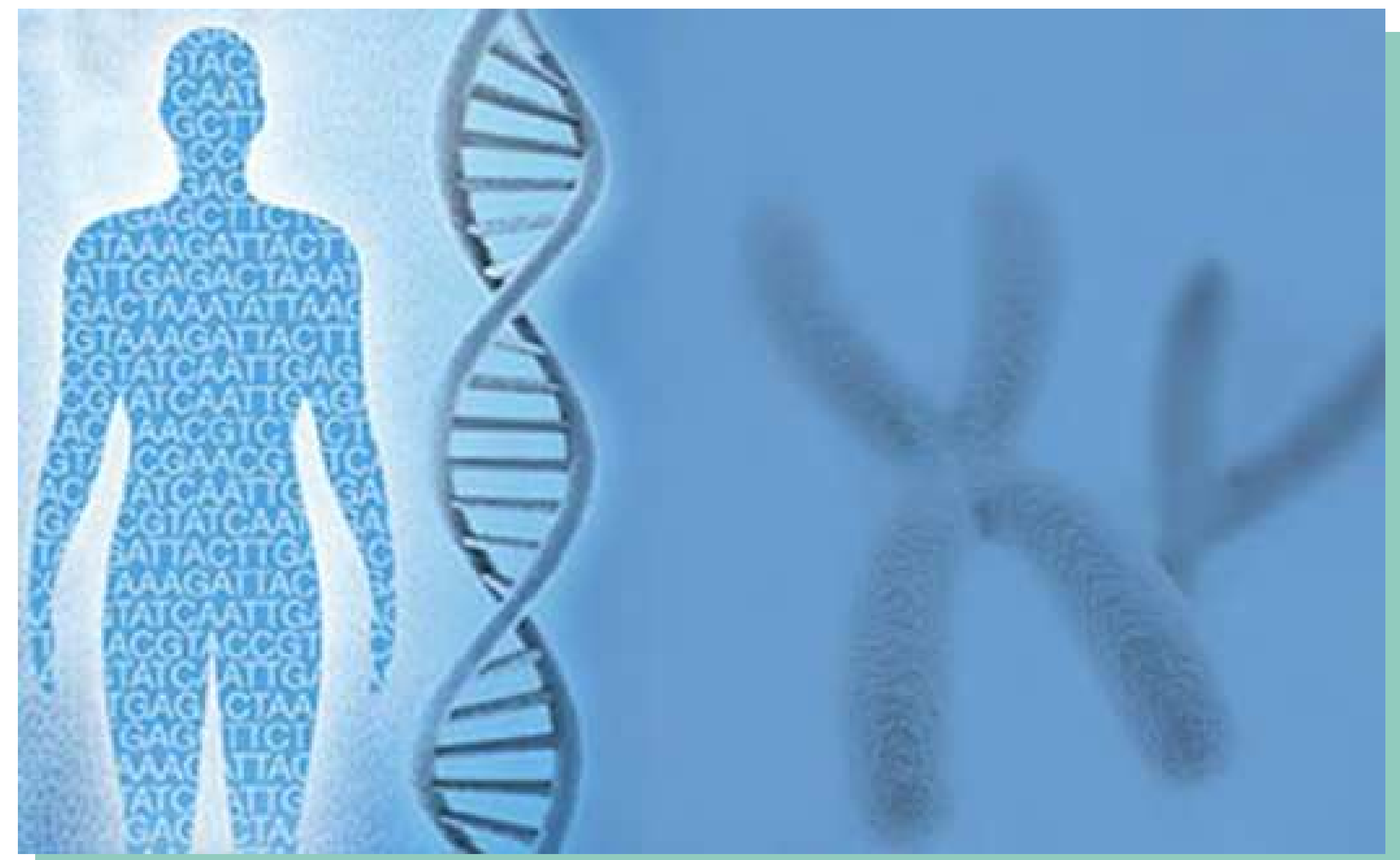




# C. Transforming Cancer Care through Networking, Alliance Building and Breakthrough Collaborations

## 📍 AUSTRALIA

Australia is still in the process of establishing a National Parent Group network umbrella, as each of the different states have been busy with their own individual state work.



On the medical side, pediatric oncology units of hospitals across Australia (including the Royal Children’s Hospital, Melbourne), who treat the 950 children and adolescents who are diagnosed with cancer every year, initiated the Zero Childhood Cancer program. These hospitals will work collaboratively with a range of key Medical Research Institutes both nationally and internationally, for establishing a nationwide personalized medicine program for children at high risk for cancer. It will give hope to children who are at highest risk of treatment failure, by identifying the best possible tailored treatments for them.



## 📍 NEW ZEALAND

In New Zealand, CCF New Zealand commissioned a research project in conjunction with CureKids to develop a genetic test called Next-Generation Sequencing (NGS) to identify gene mutations in the cancers of eligible children and adolescents. Following the initial development of the NGS test, the clinical trial will be offered at both of New Zealand’s specialist paediatric cancer centres; Starship Blood and Cancer Centre in Auckland, and the Children’s Haematology and Oncology Centre in Christchurch. The project aims to offer therapies that are ‘more gentle’ for hard to treat cancers and will, we hope, become part of clinical practice in New Zealand. Both organisations have committed a total of \$1.25million over five years.



## 📍 AUSTRALIA

In August 2017, the Australian Government Senate Inquiry, “Funding for Research into Cancers with Low Survival Rates”, included two members of the Royal Childrens Hospital (Melbourne) Parents Advisory Group. This special body came up with a report on the impact of health research funding models and the availability of funding for research into cancers with low survival rates. Following this inquiry, the Australian Government pledged AU \$100M towards this research initiative Pediatric Oncology Counselling Network.





In New Zealand, CCF NZ, together with their National Child Cancer Network and one of the universities in New Zealand, developed a framework for a nationwide counselling service, specifically for children and families of children with cancer. This is due to the fact that the needs of this group are quite distinct and there is a growing need for this type of support in various communities. The project has developed a business case for the establishment of a framework and pilot programme and are working with other NFPs to determine an appropriate funding model.

## D. Innovative Psychosocial Support Programs

CCF NZ has a national programme of SIBS (Specially Important Brothers and Sisters) camps in New Zealand; 4 very successful camps were held. These camps have a mix of strengths based workshops and games, fun and kinship for the siblings of children with cancer. CCF NZ also held five Mothers Retreats and a Dad's weekend. These special purpose retreats are a mixture of physical challenges and workshops run by specially trained facilitators. It enables parents to build new and deeper connections with others who have kids still in treatment; it provides them with a space to focus on themselves, instill/renew their confidence and empowers them to move forward. Feedback from all the retreats has been overwhelmingly positive.



The separation of families when a child is in one of the two treatment centres in New Zealand is one of the biggest challenges – both for those in hospital and those at home. CCF NZ continued their Keeping In Touch programme (KIT) where with financial assistance from Z Energy (a NZ owned fuel company), Vodafone and Apple, children with cancer admitted to the treatment centres were provided with an iPad that has specially designed “boredom buster” apps, distraction apps and education apps all appropriate for children 5 – 12 years. Access to social media sites is restricted but the ability to skype friends and family has been a great boost to the morale of both the children and the parents. CCF NZ has also installed a custom-designed library of books for both children and parents. The iPads come in destruction proof cases and the children have the iPads on loan for as long as CCF NZ and their families deem them useful in their personal situations. They have proved extremely useful and popular.

## MOST CHILDHOOD CANCER ARE CURABLE



CCF NZ has also developed and introduced a Distress Screening Tool as part of this National Counselling project. This is for use of their Family Support Coordinators, in order to determine, with some degree of accuracy, whether a parent/caregiver needs professional counselling. At present, the tool is being piloted in Auckland.





### Online Shopping

Traditionally CCF NZ have assisted families, based on their personal needs, in meeting their grocery needs from time to time. In the past, they provided vouchers for use at their local supermarket. However, they found that, very often, the parents find the stress of going shopping as high as the need for financial assistance with groceries. So they started to introduce online shopping wherein CCF NZ places an order, depending on the family's needs, that will be delivered to their door at an agreed time. They intend to grow this option to introduce healthy eating options for families whose diet needs improvement. CCF has started working with a nutritionist on the basis of such options.



<http://ebooks.edocumentonline.com/DDP/cc/>

CCF NZ has enhanced the Nutrition Booklet that they have available for families and which was compiled with the assistance of students from Auckland University and the Paediatric Dietitian at Auckland City Hospital. For the first time, they have produced it as an e-book. This is the link to the page on their website – Helping Your Child Eat Well.

## E. Innovations in Developing a Positive Care Environment

### Ringing in success, joy and hope.

The Parents Advisory Group at the Royal Children's Hospital, with support from the KOALA KIDS Foundation, installed Two Celebration Bells in the cancer centre.

The Celebration Bell is a symbol of success, hope and new beginnings. Signalling the sound of the celebration bell echoes the completion of treatment and the end of a child's stay at the hospital.

The triumphant sounds of the bell inspire other children and their families; it signals that the cancer journey can be successfully completed and cancer overcome.

One parent on the ward captured this by saying "we so look forward to the time we get to ring the bell". This ringing of the bell is important to the staff as well as it enables them to acknowledge the joyful aspects of the Childhood cancer treatment journey.



### Lighting up the World of Children with Cancer, One Child At A Time.

In 2016, Bryce, a 9 Year old, started a project to share love, hope, happiness and comfort with children still in treatment for cancer and their families. He decided and committed to give every child diagnosed with cancer in Australia, a very special Super Max the Turtle, a night light designed especially for children with cancer. In 2017 he was able to reach 800 children. He plans to continue this on a yearly basis and hopes to include New Zealand in the very near future. -That will be 1200 children who will be all connected together through these comforting magical little lights. [www.supermaxandbryce.org](http://www.supermaxandbryce.org)





# CHILDHOOD CANCER INTERNATIONAL ASIA

## Better Together

### COLLABORATION OF CANCER CHAMPIONS IN ASIA

The CCI participants not only learned from the exchange of experiences and insights during the 2 days conference but also enjoyed the interaction with passionate people caring for children/adolescents with cancer from Asia and other countries. The enthusiasm and high degree of involvement of the participants is the fuel in making this an exceptional and quality conference.

The CCI Asia Conference Organizing team introduced some innovations in this years conference. Here are some highlights of the CCI program:

A joint CCI-SIOP Nurse session on "Roles and Challenges of Family, Extended Family and Nurses". It was an excellent exchange of knowledge and experience between the nurses and families.

A presentation, plenary dialogue and panel discussion on "Patient Safety and Pharmacovigilance" led by CCI Chair Carmen Auste and CCI Asia Head, Benson Pau .

The CCI ASIA Survivors Consensus Statement which they declared during the main SIOP closing ceremonies.

The playing of the We Are One song during the opening .

This was the third year we continued to have the very inspiring

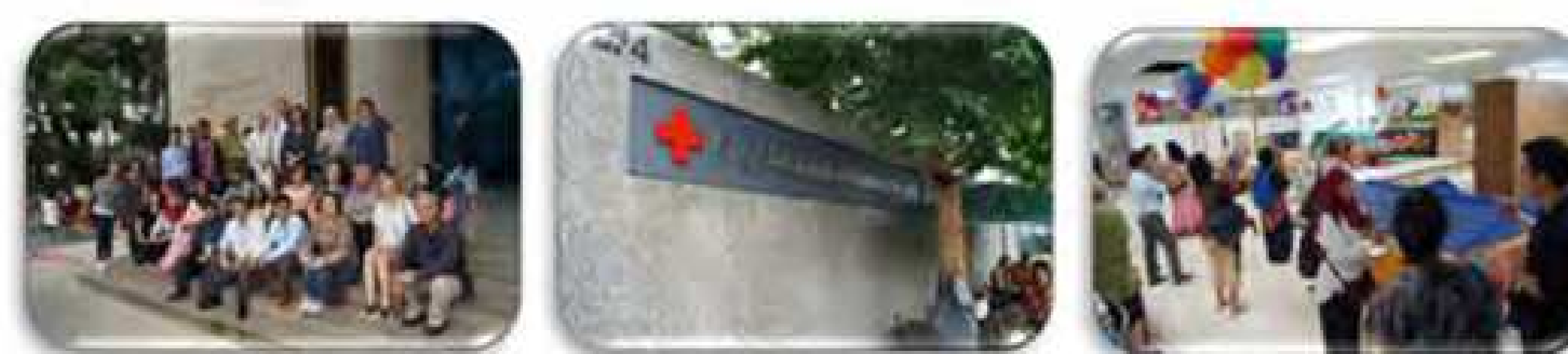
session focused on "Stories of Courage and Hope" by the survivors. 5 survivors from Brunei, China, India and Thailand shared their journey and the challenges they experience. All of them showed their creative and positive energy in the way they shared their touching story which made the start of Day 2 highly meaningful.

2 separate workshops were held in the afternoon of Day 2 with all the foreign participants separated in 4 groups discussing "What CCI Asia members can be acting on and achieve together?" and the Thai participants discussing and mapping the "Desired future development and collaborations for the Thai Parents & Survivors Support Group". The 2 workshops achieved excellent outcomes with strategic actions identified in addressing Nutrition, Capacity Building, Pain & Palliative Care Management, Survivor Care and Follow Through. The Thai participants agreed to form the First Thai Childhood Cancer parent group with support from the medical team and The Wishing Well in order to address the issues they have discussed.

Dr Issarang Nuchprayoon, the Founder of Wishing Well Foundation, sponsored the unforgettable Meet & Greet cum CCI dinner in Silom Village and also the simultaneous translation to enable the Thai participants to listen, learn and engage in our conference.



On 28 May 2017, more than 30 participants visited the King Chulalongkorn Memorial Hospital. Many thanks to Dr Kanhatai and Dr Piti for showing us around.



The 2018 CCI International Conference is going to be held at Kyoto, Japan in November, therefore, the 12th SIOP-CCI Asia Conference will resume in 2019. We look forward to another great learning experience and most inspiring conference.



The 11th CCI Asia Regional Conference was successfully held on 26-27 May 2017, in the Centara Grand Convention Center at CentralWorld, Bangkok, Thailand . It was run simultaneously with the 11th SIOP Asia Congress under the theme of "Optimizing Care for Asian Childhood Cancer". More than 100 participants from 17 countries( Australia, Bangladesh, Brunei Darussalam, China, Indonesia, India, Iran, Japan, Korea, Malaysia, Myanmar, Nepal, Philippines, Singapore, Vietnam, United Kingdom, and host country Thailand) attended the conference. There were 55 parents, survivors and carers from foreign countries, representing 20 childhood cancer organizations. The remaining 45 were from Thailand.



# INDONESIA

## CCI Board Members Engage with Indonesia Ministry of Health and Indonesia Childhood Cancer Stakeholders

CCI Chair (Carmen Auste), Vice Chair (Ruth Hoffman), CCI Asia Head (Benson Pau) and CCI Board Member from Oceania (Mary Mc ) met with Mrs. Niken Palupi, Head Sub-Directorate of Cancer, MOH Indonesia. In the meeting, CCI led awareness raising campaigns on ICCD (February) and Light Up Gold (September, International Childhood Cancer Awareness Month) were discussed. The Minister expressed her desire and willingness to spearhead and support these initiatives for Indonesia.



CCI meeting with MOH

The Board Members also participated in the first Indonesia Childhood Cancer Multi-Stakeholder Dialogue with the MOH and WHO local representative. The various stakeholders shared their key initiatives, challenges and needs on the care and treatment of childhood cancer and discussed how to facilitate collaboration with MOH, technical guidance and support of WHO and better coordination and complementation of efforts



CCI Board and Multi-stakeholders Dialogue Participants

CCI and the participants in the First Indonesia Childhood Cancer Multi-Stakeholder Dialogue.

## Inauguration of new family accommodations for parents/ carers of children with cancer in Malang and in Jakarta

YKAKI launched its 9th family home in Malang Indonesia, with support from ALFAMART ( a local sponsor) . This new accommodation Rumah Singgah ALFAMART was inaugurated by the Malang Vice Mayor, in the presence of CCI Chair and YKAKI leadership.



In addition, a 10th family home and accommodations was also opened up in Jakarta. This was an expansion of their current family home and was meant to assist the growing number of families needing a free place to stay during treatment and follow through of their kids with cancer.





# FIGHT like a kid!



## MYANMAR

### CCI ASIA GROWTH FUND INITIATIVE

#### Family/Parents Group Capacity Development

During the 2016 National Childhood Cancer Control Workshop held in Yangon and Naypitaw, CCI was designated as lead for the outcomes related to the formation and capacity development of a parents/family group in Yangon and Mandalay (where there are childhood cancer tertiary health facilities). The National Childhood Cancer Control Workshop was led by the Ministry of Health and WHO County Office, with support from St Judés Medical Center and World Child Cancer. The discussions led to the development of a country action plan for scaling up and strengthening childhood cancer care in Yangon and Mandalay.

Subsequently, the Golden Hands of Hope family group was formed in Yangon Childrens Hospital.

In January, 2017, CCI ASIA mentor team interacted with parents/families from the Yangon Children’s Hospital (YCH) and Mandalay Children’s Hospital (MCH) and held coaching session for the core parents team. This periodic visit is meant to support the growth of the parent group. Besides meeting with the parent groups, CCI met with local stakeholders who can support the parents group. One of these groups was the Myanmar Story Tellers organization which will collaborate with CCI in the development of story books for children with cancer as well as train parents/carers in storytelling. They also committed to join activities for children with cancer and their families.



To address the Yangon Childrens Hospital (YCH) medical teams expressed need for a capacity building training program for Hematopoietic Stem Cell Transplantation (HSCT) for nurses, CCI Asia in collaboration with the European Society for Blood and Marrow Transplant Nurse Group (EBMT NG), Nurses No Frontiers Association (NNF) and YCH, held a 2 day training in December 2017. The two-day event introduced the nurses and the physicians of Myanmar to basic information on bone and marrow transplantation, infection risks and management, supportive care and nutrition management. More than 100 nurses from YCH and MCH attended the training course, alongside a number of local physicians.

#### Capacity Building of medical staff from YCH & MCH



#### Capacity Building of medical staff from YCH & MCH

In December, children with cancer and their families in MCH, with the generous support of AIS, enjoyed a very memorable Christmas celebration with magic shows, dancing and Christmas presents for the children.



Kids from MCH & MGH enjoying the Christmas Party



# CHINA

## Pain Care Management Project for Hematology & Oncology Centre of Beijing Children's Hospital

Under the patronage of CCI, the support from CCI ASIA Growth Fund and the leadership of Benson Pau, CCI Asia Head, the Pain Care Management Project for Hematology and Oncology Center in Beijing Children's Hospital, China (BJCH) was launched in 2015.

The project was led by Dr. Zhou Xuan, Oncologist of BCH, and aimed at (1) improving the understanding, ability for assessment and handling of pain management for children with hematology and oncology diseases in Hematology and Oncology Centre of BJCH; (2) improving understanding, ability of assessment of pain management among parents and carers of children with cancer in the Centre; (3) improving the atmosphere and environment in the Centre to help relieve children's pain during their stay in the hospital.



*Pain Management Training program kicking off the project, participated by 180 doctors and*

In 3-13 January and 16-20 January 2017, four head nurses from the BJCH were invited to join a 10-day and 5-day on the job training and coaching, held in the Prince of Wales Hospital in Hong Kong.



The capacity building initiative was led by Dr. Chi Kong Li, SIOP Asia President. It aimed to enhance the nurses practical knowledge on the diagnostic processes of various kinds of cancer and their treatment including bone marrow transplantation.



During the course of the Project, Dr. Zhou was inspired to initiate the "China Pediatric Palliative Care Cooperative Group", devoted to broaden the knowledge of the professionals through training of medical staff, parents/carers and families and accelerate the promotion of palliative care to the community. An initial 32 hospitals joined the group. Booklets with the WHO guidelines concerning palliative care have been translated into Chinese, distributed and used by the member hospitals.



On 16 September 2017, a 1-day training for nurturing the Group was held with the support of Dr. Zhou Xuan and her team. The topics included pain and palliative care management and implementation of hospice services for end-of-life patients. There were over a hundred participants including medical team from 47 hospitals across 23 provinces and regions in China.

**you never know  
how STRONG you are  
until being STRONG  
is the only  
choice you have**





# INDONESIA

## Phase 1

### *Basic Orientation on Childhood Cancer with Early Warning Signs*

YKAKI in collaboration with the Public Health Faculty of Thamrin University, Dharmas Cancer Hospital and Ministry of Health, Sub Directorate for Cancer conducted a 2 day "BASIC ORIENTATION ON CHILDHOOD CANCER FOR WEST JAVA PROVINCE AND DKI JAKARTA PROVINCE" from 25-27 February. The first day was participated in by primary health doctors while the second day was for cadres from the women empowerment local initiative. Close to 1000 participants attended the 2 trainings. This project was financed by CCI- ASIA Growth Fund , Roche Indonesia and YKAKI (CCI lead organization in Indonesia for the project).



The training is part of an action research study which aims to evaluate the effectiveness of basic orientation on childhood cancer (level-1 training, level-2 training) and community based public education in increasing childhood cancer related knowledge, attitudes and practices (KAP) of local communities in Bekasi and Depok, West Java, North Jakarta and East Jakarta.



*Participants during the 3 days training*

A follow through 3 day Train the Trainer on Early Warning Signs of Childhood Cancer was conducted for health professionals, healthcare workers, cadres, volunteers and civil society. The EWS (Indonesia version) has now also been officially accepted and endorsed by the Ministry of Health for use in Indonesia. The EWS development is the result of a joint collaboration between CCI, UICC and SIOP.



*Early Warning Signs leaflets*



# LEBANON Chance Association

## A. Innovative Awareness Raising and Social Advocacy

### Never Give Up : Climbing Our Mountains

Fighting cancer is like a mountain to climb, especially for children needing specialized treatments and tailored care. This year, six members of the Lebanese American University Survival (LAUS) Team, made the successful ascent and reached the top of Mount Elbrus in Russia, Europe’s highest peak under the motto “Never Give Up”.



This was a remarkable achievement, which these brave climbers achieved in collaboration with CHANCE association, to support and inspire children fighting cancer at the LAU Medical Center-Rizk Hospital .

Researches and studies have revealed that among the best tools to battle cancer are a positive attitude : the motivation and will to survive and continue to fight. The Never Give Up Expedition was a source of great motivation and inspiration for the children with cancer.

The LAUS team sent daily personalized messages to children from Elbrus, creating a parallel between the step-wise progression of the climb and the perseverance of these brave young patients. In addition, this synergy raised nationwide awareness for the children with cancer through social media posts where many people could follow the daily progression of the expedition. The team’s climb and the children’s fight was being made hand in hand, both had mountains ahead of them, both helping each other to keep going. The bond formed between the children and the Survival Team was striking.



The words of the young patients helped the team members through periods of fatigue, while the messages of endurance and strength from the team on the mountain brought encouragement and smiles of joy to the children.

For the climbers the courage of the children became their inspiration. How could they fail when children fighting cancer were willing them on?

CHANCE association president, Dr Roula Farah summarized this inspirational project so poignantly,

### Honoring and Recognizing Mothers of Children with Cancer

Behind every child fighting cancer, there is a mother that believes in the power of maternal love in moving mountains and making dreams come true. This year, faithful supporters of CHANCE Association gathered for a brunch to celebrate and honor the mothers of cancer survivors. An “Ideal Mother” award was given to each of the mothers of the sick children. This symbol recognized their courage and dedication and acknowledged the important role they play in their child’s cancer journey. It also captured their impact on their child’s appetite for life and endurance in the face of painful and oftentimes restrictive treatments.

In addition, five young cancer survivors and their mothers were supported by CHANCE Association to undergo a week long spiritual journey in Europe.

## B. Nationwide public awareness lecture series by CHANCE Association



CHANCE association launched this year, all over Lebanon, a series of interactive lectures, directed to the general public, raising awareness about the different causes of cancer in children and adults, pointing to the importance of prevention through a healthy lifestyle and the recognition of the early warning signs of childhood cancer.



# LEBANON Chance Association ACTIVITIES 2016 - 2017

## LAU NEVER GIVE UP BRAVING THE STORM TO SUPPORT CHILDREN WITH CANCER



**Under the motto “Never Give Up” LAU’s Survival Team reaches the top of Mount Elbrus and the hearts of children fighting cancer with the CHANCE Association.**

Fighting cancer is like a mountain to climb, especially for children needing specialized treatments and tailored care. This year, on their second “Never Give Up” Expedition, six members of the LAU’s Survival Team made the successful ascent of Mount Elbrus in Russia, Europe’s highest peak! This was some achievement, but these brave climbers achieved their feat **in collaboration with CHANCE, to support children with cancer at the LAU Medical Center-Rizk Hospital!**



Among the best tools to battle cancer are a positive attitude and the motivation and will to survive and continue to fight. The Never Give Up Expedition was a source of great motivation for this group of children with cancer. The team sent daily personalized messages to the children from Elbrus, **creating a parallel between the step-wise progression of the climb and the perseverance of these brave young patients.** In addition, this synergy raised nationwide awareness for children with cancer.

The team’s climb and the children’s fight was being made hand in hand, both had mountains ahead of them, both helping each other to keep going. The bond formed between the children and the Survival Team was striking. The words of the young patients helped the team members through periods of fatigue, and the messages and show of strength from the team on the mountain brought encouragement and smiles of joy to the children.

For the climbers the courage of the children became their inspiration. How could they fail when children fighting cancer were willing them on?

Alan Kairouz, Survival Team Leader, summarized so poignantly,

**“We pray such an expedition would also be a message to motivate the little ones to push on, look forward and Never Give Up. And pray that this expedition and our coming expeditions would further encourage others to follow on the same path in helping children with cancer in any way possible.”**

### THE SURVIVORSHIP PASSPORT-

Dr Roula Farah initiated customization of this for Lebanon and Asia survivors. The survivorship passport started in the EU and is a document to be given to the individual cancer survivor after the elective end of therapies. It is paper and electronic based, written in a simple way and containing the survivors cancer history/ therapy information and current health status . It also provides advice and guidance on patient-specific long-term follow-up care for possible late effects.

The recommendations are color-coded, depending if they are strong, moderate or weak guidelines and they address issues such as cardiomyopathy, screening for secondary cancers, gonadal function, hearing and mental disabilities, bone, renal and hormonal toxicities and fertility .





# INDIA

## Can Kids - Kids Can

### A. Advocacy

#### National Advocacy - Lets Go Gols India

Punjab Goes Gold in 2017. 10,000 Gold Ribbon were pinned on individuals to sensitize them and build awareness on childhood cancer importance. In addition, this year 124,000 pledges were raised to make Childhood Cancer a National Child Health Priority. A Childhood Cancer Awareness Exhibition was held at Patiala and pledges were received from prominent people like Honourable Governor of Punjab, Chief Secretary of Punjab, Principal Secretary Punjab

#### Child Rights based Advocacy

**Right to Health-** Every child is entitled to the best standards of health care. In India not all health facilities are following best standard practices for quality and safe childhood cancer treatment and care. Thus, we have launched the Campaign called I Deserve to advocate the improvement of quality of care in treatment centres and hospitals.

**Right to Education-** A recent survey revealed that 85% of children with cancer in India had missed out on education for at least one year. CANKIDS is providing non formal and formal education to ensure this right. We also conducted 5 Debates on whether Childhood Cancer should be included in the Disability Act or not? We found that survivors are not yet ready to be included in the PwD Act but they want/need the following. a) ongoing school in hospital and through home schooling and individualized education programs during treatment; b) be allowed to take important exams while in hospital and in authorized centres and be given extra time for exam writing; c) no child with cancer and /or survivor should be penalized for lack of attendance for an exam; d) no survivor should be denied promotion; e) no child should be denied admission to a school or competitive exams because of cancer.

**Right to Childhood-** Every child deserves their childhood, Every child has a right to play, be happy, to develop fully, to enjoy equal opportunities. In line with this right, CANKIDS is developing child friendly wards; we are providing Nutritional Support, and ensuring best practices in treatment. We try to provide the healthy, safe and energizing environment to get cure and to grow.

**Right to Pain Free Treatment & Palliative Care-** Cancer treatment is painful. Through our pharmacological and psychosocial interventions we try to reduce the pain and suffering of children with cancer and the distress of their families/carers.

**Right to Be Heard-** Our model of family engagement is key to ensuring the child's right to be heard. With 1,155 parent and survivor members, they advocate through our campaigns and encourage the children to express their feelings.



### State Focused Change for Childhood Cancer

The 6 States where Change for Childhood Cancer projects have been initiated since 2015-2016 and are still ongoing are Rajasthan, Tamil Nadu, West Bengal, Uttar Pradesh, Delhi NCR. For 2017, focus was in Punjab. CanKids signed a 5-year MOU as knowledge and technical partner with Government of Punjab on September 14, 2017 in the presence of Honourable Health Minister Government of Punjab to make change for Childhood Cancer a Health Priority in Punjab. An MOU was also signed with Baba Farid University of Health Sciences Faridkot on November 29, 2017. In addition, a Childhood Cancer Sensitization Workshop was chaired by Honourable Health Minister Government of Punjab and was attended by around 450 people, in order to create awareness and sensitize government leaders, doctors, students, nurses, ash workers, and other government officials. A local social advocacy and awareness car rally was also held travelled through 15 districts of Punjab. Awareness and Access to Care Programs were conducted during the Rally between Sept 24th to 28th in 3 medical institutions, communities and colleges.



### B. SURVIVORSHIP PROGRAMS:

KidsCan Konnect has a total of 467 members. In addition new KCK Chapters were set up in 3 cities- Ahmedabad, Kolkata, and Mumbai. There are now a total of 9 KCK Chapters.

Survivors participated in 3 Mentorship Talks, 3 National level conferences, and 2 international level conferences; Survivor passport clinics and workshops were held in Delhi, Ahmedabad, and Kolkata to educate survivors and for one-on-one follow; 71 passports were issued. Survivors also performed in 28 Nukkad Natak (Street Plays) and Flashmobs to create awareness on childhood cancer among the general public

### C. Networking and Partnership

CANKIDS is a member of Childhood Cancer India Social Support Network Group (CCISSN) which has 50 members from across India. In November, 2017, it conducted the annual meeting of PHOSSCON, with 35 NGOs and 144 participants.

CANKIDS is also part of Fight RB India Stakeholder Group- which has 12 participating members who work together with the objective of improving care of retinoblastoma patients. CANKIDS partners and supports research activities together with the Indian Pediatric Oncology Group and 17 medical advisors. CANKIDS also sponsors and hosts Regional Pediatric Oncology Forums; 3 Regional Pediatric Oncology Forums were held: North India Pediatric Oncology Forum (NIPOF), East India Pediatric Oncology Forum (EIPOF) and Tamil Nadu Puducherry Pediatric Oncology Forum (TPPOF).



## SNAPSHOT of INDIA

### Childhood Cancer Care Initiatives

#### A. Parent / family homes, owned and managed by CCI member organization or undertaken in collaboration with a partner

There are a total of 48 centers across India. Of these, 40 are managed by CCI members - CanKids.. KidsCan (5, including a pediatric palliative care center) and St. Jude's Child Care Centers (35). These centers are located in Delhi, Mumbai, Kolkata, Chennai, Trivandrum, Hyderabad, Jaipur, Vellore, Pondicherry, Kozikode.

#### B. Hospital-based schools / learning facilities run / managed by CCI member org or other allies/stakeholders

There are a total of 3 formal learning facilities in India. Two of these are run by CanKids (1 inside BJ Wadia Hospital Mumbai and another, outside the hospital, called CANSHALA. St. Jude's, another CCI member, runs a non formal education program. In addition, there are 10 other non CCI organizations who are working to provide non-formal educational program for children with cancer both within and outside of the hospital.



#### C. Kids with cancer and families receiving nutritional support

Four CCI members, CanKids...KidsCan, Aroh/Giving Hope, IMPACCT Foundation and St. Jude's are providing nutritional support services to children with cancer. The Jiv Daya Foundation is also running a joint program with CanKids for RUTF.

CanKids alone provided nutritional support to a total of 2,314 patients. CanKids runs a full nutritional support program, currently in 15 centers all over India, in which comprehensive nutritional support services are provided, including RUTF.

The average age of a child diagnosed with cancer is 6...



#### D. Hospital-based schools / learning facilities run / managed by CCI member org or other allies / stakeholders

There are 7 CCI member organizations in India providing medical support to children with cancer. This includes: AROH/Giving Hope, Hope Child Cancer Foundation, Eshwar Foundation, Sahayta Charitable Welfare Society, Cancer Patients Aid Association, IMPACCT Foundation, Indian Cancer Society.

On its own, CanKids...KidsCan provided direct financial support for treatment to 5,265 patients in the amount of USD \$762,000. CanKids social support team also helped 1,037 patients to avail of financial treatment support for treatment through indirect sources such as government schemes in the amount of USD \$2,166,00. CanKids provides support for diagnostics, medicines, treatment supportive care such as blood products, and direct treatment costs such as surgeries and Bone Marrow Transplants.

#### E. Hospitals assisted and provided with support

There are a total of 84 hospitals in India where children are treated for cancer that are being supported by various NGOs (CCI members and non-CCI members/allies). These hospitals are spread across 35 Cities in 20 States and Union Territories in India. CanKids provides support for 45 hospitals across India.





# JAPAN: AFLAC Parents House

**For children and their families who are fighting childhood cancer and other serious illnesses**

Children fighting pediatric cancer and other serious illnesses have to travel great distances to gain access to specialist hospitals in such big cities as Tokyo and Osaka. To mitigate the financial burden of transportation and accommodation expense on parents with sick children, we operate two lodging facilities in



(Kameid)

(Asakusabashi)

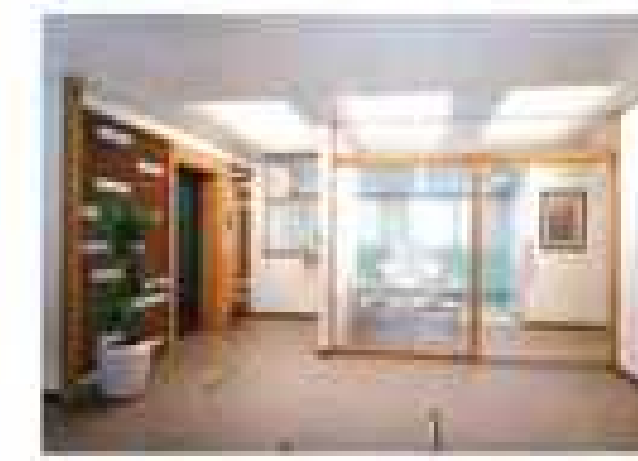
(Osaka)

These Parents Houses has unique functions such as.

- 1. Home away from home**  
The Parents House not only provides accommodations but also serves as a place where families can relax and feel at home.
- 2. Consultation & support**  
CCAJ's social workers are always on stand by to give families advice and support.
- 3. Information gathering**  
The library & information corner has a wide range of publications, mainly on pediatric cancer, to help families learn, understand more and be prepared for their cancer journey.
- 4. Research**  
The Parents House seminar room is used by medical professionals for research-related activities. A full range of office equipment and screen is available for use.
- 5. Interaction**  
The Parents House brings together families, doctors, nurses and social workers to network and exchange information as well as provide support.
- 6. Information dissemination and Public Relations**  
The Parents House disseminates information to the general public on childhood cancer to promote greater understanding of the issues faced by sick children and their families in the hope of gathering wider public support.

## Photo Introduction of the Parents House

### 1F Entrance



Entrance hall (Asakusabashi)

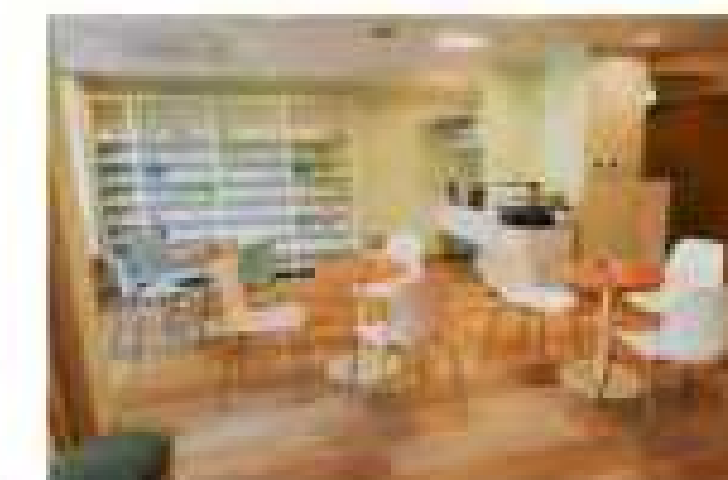


CCAJ's office (Asakusabashi)

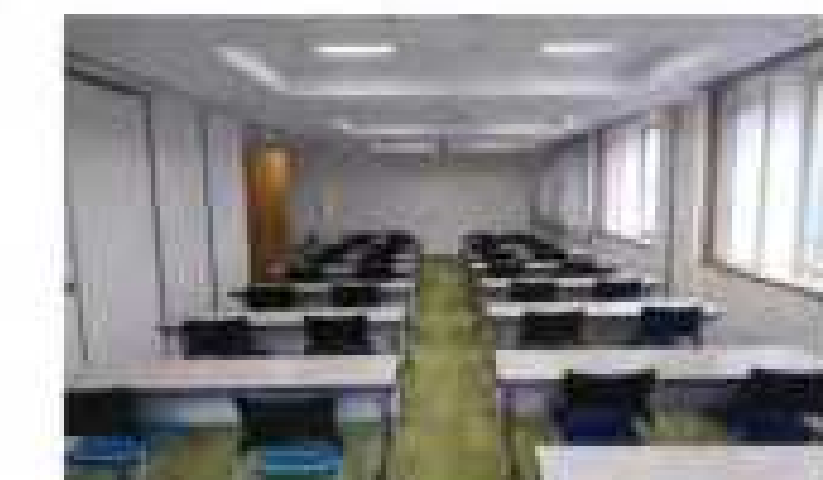


### 2F Seminar room

This floor provides space for socializing and learning. The seminar room which accommodates maximum 60 people is used for a variety of activities.



(Rounge: Kameid)

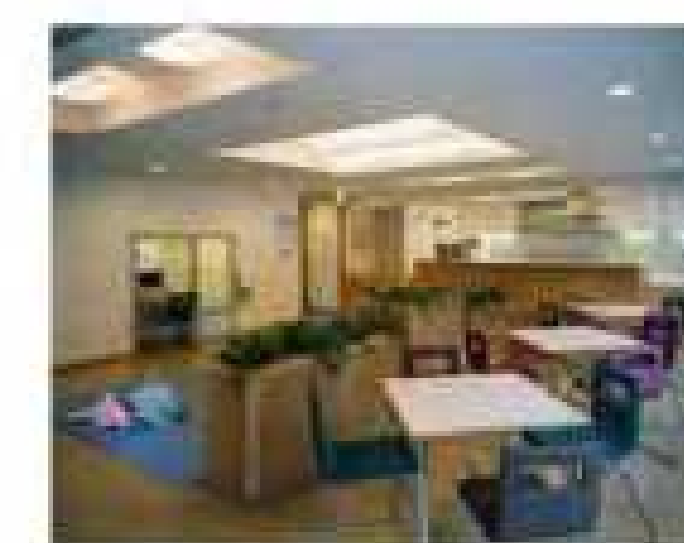


(Seminar room: Kameid)

### 3F Floor for Family Gatherings

#### Kitchen & Dining Area

Parents can keep a watchful eye on the play area while preparing meals.



Play Area

Play tools which are regularly sterilized are available for children.



(Kameid)



(Asakusabashi)

### 4F, 5F, 6F Accommodations



Western-style room



Japanese-style room

### 7F Utility Floor

A variety of utilities is provided to support daily life at the Parents House including a laundry room equipped with washing machines. Families are invited to relax at the terrace reading books picked up from a bookshelf at the Information Library while washing.



(Kameid)



(Asakusabashi)



(Laundry room)



# BANGLADESH:

## ASHIC Shelter to Reduce Abandonment/Drop out and Improve the Survival Rate of Childhood Cancer in Bangladesh

Cancer is a scary word for all, especially for low and middle income countries such as Bangladesh. The real data in Bangladesh remains unknown but it is said that approximately 15,000 children are diagnosed with cancer annually. In most cases the diseases are detected in their advanced stages, leaving limited avenues for curative treatment. A very high percentage of the affected children cannot pursue full treatment due to financial constraints, late diagnosis and ignorant parents who may not fully understand the gravity of the disease. Moreover, rural patients face hardships with accommodation and other logistical requirements for the long-term treatments available only in metropolitan areas, such as Dhaka.



In the 90s, the present Bangabandhu Sheikh Mujib Medical University (BSMMU) Hospital was the only treatment center for Childhood Cancer in the country. ASHIC discovered that the abandonment/dropout rate of the childhood cancer patients under treatment, coming from across the country, was very high because of accommodation problems in Dhaka city. As such, in 1999, we thought of establishing a home away from home (Shelter) near BSMMU Hospital to support the commuting families and encourage them to complete their treatments.



ASHIC Shelter started its journey in 2000 with a 15 bed facility for the children and their mothers to provide accommodation free of cost; the facility also had an additional 6 beds for accompanying male guardians. Reports and studies done recently indicate that the Shelter has had a direct impact on reducing the abandonment/dropout rate from 80% to 35% and also in contributing to improving the country's survival rate from 3-10% to 40-45%.



Since the facility is unable to cope with the increasing demand for accommodation, in 2017, ASHIC bought a 300 sq. metre apartment and designated 20 beds for children and their mothers and 6 beds for the accompanying male guardians. This new facility is now catering to families able to pay a nominal fee so that the operational cost can be maintained. It is beginning to get good response and we are confident that the new Shelter will definitely contribute to further improving the survival rate of Childhood Cancer in Bangladesh.



For the past 2 decades, the Shelter has proven that it is an essential part of the support system for those coming from the rural areas for treatment in Dhaka and is essential to having better survivorship outcomes. We hope that the ASHIC Shelter serves as a replicable model for other low income countries struggling to improve their pediatric cancer survival rates.



# STORIES OF HOPE

## SINGAPORE

### Emma, the Changemaker!



**Children's  
Cancer  
Foundation**

When Children's Cancer Foundation (CCF) beneficiary, Emma Tat-yana D/O Mohamed Rashied, was diagnosed with thoracic intra medullary spinal cord tumor in 2015, she was faced with countless medications and side-effects such as vomiting. The once cheerful and confident child suffered from low self-esteem and was frightened by thoughts that she would never be able to walk again.



Farlinah, Emma's mother was very concerned. "I needed her to see that life can go on and for her to have something to look forward to everyday," says Farlinah. She decided to enrol Emma into CCF's learning centre, Place for Academic Learning and Support (PALS), which serves as a transitional platform to bridge the learning gap between the treatment phase and normal schooling routine. There, Emma could make new friends and catch up on her school work.

**Every two minutes  
a child is diagnosed  
with cancer**



**"When I was studying at PALS, my favourite activities were the English classes, baking workshops, playing badminton and spending time with my friends during recess. I met people who knew what I was going through. Some of them had been in my shoes as well and they wanted to help me achieve my goals," shares Emma.**

Farlinah noticed that her daughter became more confident after attending PALS. Emma also grew to be more expressive, and even volunteered to lend her vocals to the theme song of Childhood Cancer International's #Child4Child project, 'We are One' to commemorate International Childhood Cancer Day on 15 February 2016. Farlinah attributed this change to the holistic curriculum at PALS.



At PALS, students not only attend academic coaching based on curriculums set by the Ministry of Education, but also therapeutic group work, psychosocial education as well as enrichment activities. Some examples include experiential learning sessions, funfit classes and character building lessons aimed at empowering them with coping skills to overcome their challenges.

Emma attended PALS for a year before returning to mainstream school in end 2016. She hopes to be an inspiration to other children who are suffering from cancer. "In the future, I hope to make the road to recovery a less bumpy one for other children with cancer. I want it to be a smoother road for other children who have cancer like me."



# STORIES OF HOPE

## PHILIPPINES

### Lessons from a grateful heart: The journey of Popoy and Mommy Jin

Popoy Marollano was two years old when he was diagnosed with acute lymphoblastic leukemia, stage 2, five years ago. His mom Jin recalled that the doctor assured them of a 90 percent survival rate if they followed the chemotherapy religiously. This December 2017 (his third year off chemotherapy), her son will be celebrating his eighth birthday, and he is getting healthier and taller by the day.

Funny, creative, smart—these are the words Mommy Jin feels would best describe her little boy. Being a single parent, she takes care of Popoy with help from her sister and parents, giving him a loving support system. It broke her heart when Popoy was first diagnosed in Leyte, as she was working in Cebu. They immediately sought treatment in Cebu, where Jin juggled work and family time daily.

“We were given a protocol through which I could track Popoy’s routine from time to time,” explained Jin. “It helped a lot that our doctor gave me that from the start, so that we could check on what medicine was administered. I also did some research about the effects of certain medicines, and I think that helped Popoy’s treatment succeed,” she explained.

Despite being away from his cousins, who were also his playmates, Popoy developed a sympathetic and sweet heart, which Mommy Jin believes came from his exposure to kids like him who were also suffering and in pain. Today they both volunteer at Cancer Warriors Foundation Inc-Cebu, where they can exchange stories and support fellow patients.

Even when facing financial struggles while paying for Popoy’s laboratory exams and doctor’s and hospital fees, Jin recalled that help came from all directions. Jin worked to support Popoy’s therapy, and received aid from his father. The Cancer Warriors Foundation Inc-Cebu helped her get access to free medication. Thankfully, Jin’s workplace was also very supportive and allowed her to take the day off for her son’s therapy or check-ups.

#### *Family and faith*

Family and faith helped Jin and Popoy conquer every ordeal. Whenever they both reached a low point, it was praying together, with their family and friends, that brought them strength and hope to keep going. Jin learned to treasure not only special occasions like holidays or birthdays, but even little victories like making it through a bone marrow extraction.

If there’s one thing that being a mom taught her, said Jin, it’s this: “Strength means sharing it with a little child who draws all his strength from you. We see how life is precious. Make the most of every day, and live each one as if it was your last.”

Today, giving Popoy a normal childhood is still a priority for Jin. He does household chores once in a while, and is always appreciative of any kind act. Jin likes to watch movies with him, but still makes sure he has home schooling. One of their favorite pastimes is visiting a bookstore and just flipping through picture books and reading.

More than sharing hobbies, Jin realized that they both have grown in maturity, especially Popoy, despite his young age. Popoy likes volunteering at Cancer Warriors Cebu, and is even motivated to be mindful of what he eats so he can continue helping kids like him. Whenever Jin meets parents who hope their kid will be healthy like Popoy soon, she tells them that there’s no way to go but up.

Jin advocates for more parents and survivors to contribute what they can in their community and give to those who are in need. This is true even in her hopes for Popoy. “I hope he will grow up to be of service to others,” said Jin. “That he reaches his dreams without forgetting what he had to go through to get there. I want him to always have a grateful heart, for that is the essence of his life.”





# STORIES OF HOPE

## IRAQ & ISRAEL

### Kurdistan Save the Children, Iraq “First Conference in Iraq on Improving the psychological Wellbeing of Children with cancer”

This year, Kurdistan and Iraq was faced with further political, economic, humanitarian and security instabilities due to internal conflicts. The situation created large gaps in national services, slowing down scientific developments in the region, encouraging Kurdistan Save the Children (KSC) to re-prioritise activities to fill in these gaps. Activities in the past 6 months included activities directly providing services to children with cancer, and other activities which aimed to strengthen the infrastructure for services for children.

Psychosocial Support was provided to over 200 children diagnosed with cancer across Iraq and the Kurdistan Region by the KSC team with the help of our volunteers. Regular outings for child cancer inpatients, daytrips, events to celebrate cancer treatment successes, birthday celebrations, Children’s Day Events, national holiday celebrations, exhibitions of children with cancers artwork. These consistent activities all contributed to the aim of raising morale, supporting children’s psychological and physical wellbeing, giving these children hope and strength to fight cancer while celebrating their lives and breaking cultural taboos and fears associated with cancer diagnoses.



Trainings were provided to medical staff and nurses of 3 national cancer hospitals by specialized doctors invited by KSC on disease management, hygiene, exercise, nutrition, psychological stages of dealing with cancer by patients and their families, and disease prevention. Awareness campaigns on spreading information on what is childhood cancer and signs or symptoms of childhood cancer were ongoing.

The recent economic crisis and hospital budget cuts led KSC to focus on Case Management service provision for 180 children diagnosed with cancer through the provision of financial assistance for PET scans, MRI scans, CT scans, transportation and accommodation for cancer treatments, even purchasing of Vincristine Medication supplies which had been exhausted from national hospitals.

On the 14th September 2017, KSC held its First Annual Conference on Improving the psychological Wellbeing of Children with cancer, advocating a multidisciplinary approach to treating cancer to stakeholders including the Ministry of Health and specialized oncologists of all national cancer health facilities. This conference was key in creating dialogue between parents of children with cancer, the children, and the healthcare providers to help address their concerns. The conference also contributed to strengthening communications and standardizing efforts between different national cancer healthcare facilities which has been positively ongoing since.

KSC was able to conduct these activities with the support of national donors, event sponsors and believers in the KSC cause.



# CHILDHOOD CANCER INTERNATIONAL EUROPE: Stronger Together

## A. Major collaborative initiatives

### The European Reference Network for Paediatric Cancers (PaedCan)



CCI Europe has developed a roadmap which shows the role of CCI Europe including the regional and national contact points within the network.

CCI Europe is also further developing a sub-network, which aims to meet the needs of the ERN PaedCan. It will have a mediating role between the coordinator of the ERN PaedCan and the national contact points - Patients' and Parents' groups in Europe.

A national contact point is not necessarily a national umbrella organization but should be in regular communication and collaborates closely with the other regional organizations in the country. In addition, individuals being designated as national contact points must have some desired qualifications and agree with a code of conduct regarding their representation of CCI Europe. Thus, CCI Europe will work out a "Qualification profile" as well as a "Code of conduct".



In each of the Member States, a central national contact point will be available for affected families; these contact points are the ones to whom families can address their queries, requests and clarify / resolve possible uncertainties which require advice and support.

The duty of the involved childhood cancer organizations is, to inform families about the ERN PaedCan itself and its values and also at the same time about patient rights /e.g. the right to a 2nd opinion, etc .

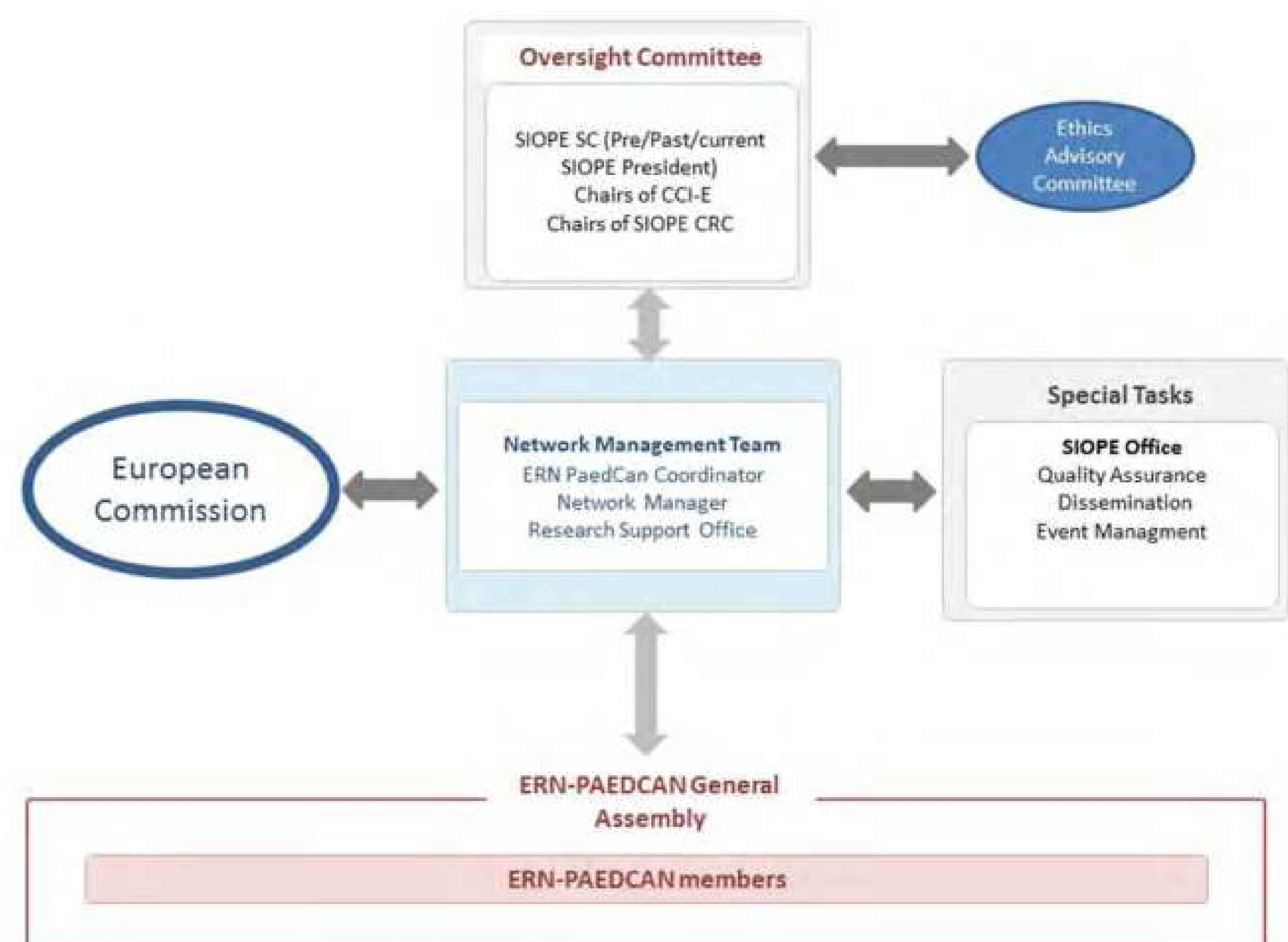
Providing safety through transparency, is the essence of their contributions.

Affected families have to know, which is the reference centre in their country, where to find the needed expertise and best treatment for their child.

If a treatment abroad should be unavoidable, there will also be a contact point for the families arriving; to support them regarding logistics and administrative issues, to catch them up psychologically and to ensure patient safety.

The CCI (Europe) & ePAG representatives (a EURORDIS initiative) for ERN PaedCan are Luisa Basset, Anne Goeres, Lejla Kameric, Anita Kienesberger and Stephanie Schremmer. They are part of the oversight committee of the network and part of its decision-making structure ; they provide the views of parents and survivors. Furthermore, they will be involved in the evaluation of the network at regular intervals and contribute to the dissemination of patient information, policy, good practice, care pathways and guidelines in close cooperation with SIOPE.

Also, information for parents and childhood cancer survivors will be improved in cooperation with Childhood Cancer International (CCI), including information on clinical trials and clinical research.





**EVERY 3 MINUTES  
A CHILD DIES FROM  
CANCER**



### **SurPass within ERN PaedCan**

ERN PaedCan will also continue to support the work on the survivorship passport, an innovative solution for follow-up and to improve transition into adulthood.

The current lack of information on many patients' medical history becomes particularly critical as children become adults or as they move to another country. The survivorship passport closes this gap by a) provision of relevant information on the medical history of patients who ended a cancer therapy, b) making survivors and healthcare professionals aware of the potential risks or late effects stemming from the previous disease and treatment received based on appropriate guidelines.



### **ERN PaedCan PARTNER project (CCI Europe as collaborating partner)**

**Aim: Creation of a Pediatric rare tumors European Registry linking the existing national registries.**

The value of the project PARTNER is based on the European wide gathering of information on treatment of VRT (very rare tumors) and the provision of the information to experts generating new guidance recommendation for daily practice.

The platform that will be created using innovative IT tools will enhance European collaboration and facilitate cross border access to dedicated expertise.

In May 2017, at the 8th CCI Europe Regional Conference in Rome, CCI Europe took the opportunity to provide the community with solid information about the ERN PaedCan and to ask for their expectations, which influenced the roadmap development significantly and will influence CCI Europe's further actions in regard to the ERN. Furthermore, the expectations were forwarded to the ERN PaedCan coordinator and project manager.

### **Harmony Project**

Healthcare alliance for resourceful medicines offensive against neoplasms in hematology.

Blood cancers, or haematologic cancers (e.g. leukaemia, lymphoma and myeloma), affect the production and function of blood cells. It accounts for about one third of cancer cases in children and for about one third of cancer deaths.

Since many blood cancers are rare and healthcare practice varies across EU, a lack of data on relevant outcomes represents a challenge for clinicians, researchers, policy makers and decision-makers alike.

The HARMONY project aims to use 'big data' to deliver information that will help to improve the care of patients with these diseases. Specifically, the project will gather together, integrate and analyze anonymous patient data from a number of high quality sources. This will help the team to define clinical endpoints and outcomes for these diseases that are recognized by all key stakeholders.

Moreover, the project's data sharing platform will facilitate and improve decision making for policy makers and clinicians alike to help them to give the right treatment to the right patient at the right time.

More broadly, the project will result in a pan-European network of stakeholders with expertise in this disease area.



#### **FACTS & FIGURES**

Start Date	01/01/2017
End Date	31/12/2021
Call	IMI2 - Call 6
Grant agreement number	116026

Type of Action:  
RIA (Research and Innovation Action)

Contributions	€
IMI Funding	20 200 000
EFPIA in kind	17 594 265
Other	1 951 352
<b>Total Cost</b>	<b>39 745 617</b>

(<http://www.imi.europa.eu/projects-results/project-factsheets/harmony>)

CCI Europe has been involved in this project since autumn/winter 2017.



## JARC (Joint Action on Rare Cancers)



Mission statement: "This EU Joint Action on Rare Cancers should be viewed as a natural framework for all stakeholders to work together to:

... prioritize rare cancer, in the agenda of the EU and Member States, with a view to national cancer plans and quality of health-care, harmonization of clinical practice, innovation through promotion of clinical and translational research;

... develop innovative and shared solutions, mainly to be implemented through the future ERNs on rare cancers, in the areas of quality of care, research, education and state of the art definition on prevention, diagnosis and treatment of rare cancers.

Recent actions involved Dissemination and conduct of 3 separate surveys to European CCI members:

- one focused on essential medicines and looked into standard treatment and care in each country
- two, determining and mapping the existence of parents/survivors organizations in the field of very rare tumours in Europe
- three, aimed to identify the educational needs of the rare cancer patients community

## B. Updates on CCI Europe Regional Committee (CCI-E ReC) Image: CCI-E ReC

### New members:



Carina Schneider (Österreichische Kinder-Krebs-Hilfe), Austria



Ludmila Hurajova Organisation: SMILE n.o. – Pomáhame s úsmevom (Slovakia)



Anne Goeres (Fondatioun Kriibskrank Kanner, Luxembourg)

## C. The European Survivors network

The working group of European Survivors was established after the CCI-E Regional Conference in Rome in 2017. At the end of 2017 it consisted of 9 Survivors from 7 different European countries (Austria, Bosnia-Herzegovina, Greece, Netherlands, Spain, Sweden and Switzerland). In December 2017 the group met in Vienna for a three-day strategic meeting to work on their goals, main action fields and working mode.

As one of their priority action fields they defined "Survivorship":

- Follow-Up and Long-term Follow-Up
- Late effects (psychosocial & somatic)
- Quality of Life
  - Follow research on Survivorship
  - Building awareness for the importance of adherence to follow-up appointments among Survivors
- Raising awareness for Survivorship-issues on European level (among stakeholders and the public)



## D. D.Highlights of major region based conferences or meetings sponsored/ co-sponsored by CCI Europe REGCOM

**8th CCI Europe Regional Conference - May 12th – 14th 2017 (Rome, Italy) Main topic: Connecting Europe**

In contrast to former conferences with a maximum of 110 participants, in 2017 160 people attended the CCI Europe Regional conference, about 50 of them survivors. More than 60 organizations/groups from nearly 30 countries were represented.

Since we believe we are together stronger and in the spirit of the conference theme of connecting and networking, not only parents and survivors were invited to attend the conference but also other partners and potential future partners, such as SIOPE (The European Society for Paediatric Oncology), the IAEA (International Atomic Energy Agency), EURORDIS (Rare Diseases Europe), Unite2Cure, the CCRI (Children's Cancer Research Institute Vienna) and Shire, a pharmaceutical company with oncology, immunology and haematology as therapeutic areas and the willingness to support parents, patients and survivors strongly.



Friday, May 12th 2017 - Kick-off

We were really happy that Carmen Auste as well as Ruth Hofmann spared no effort to be able to be with us in Rome, traveling from the Philippines and the USA. The two opened the conference in an enthusiastic and motivating manner, supported us with their expertise and experience and helped participants to get an even better understanding of what is going on in CCI.

The CCI Europe Regional Committee presented itself as well as an overview of the tasks of CCI Europe and the most important ongoing projects.

One essential and new information for the participants was that, a CCI branch for Europe will be established, legally registered in Austria. This will facilitate further growth of CCI Europe organizational capacities, application for EU program/project grants as well as resource mobilization/fund raising for CCI Europe initiatives. CCI Global/board will continue to have oversight over branch operations. However, daily operations, banking and finance, donor and partnerships management and compliance with regulatory requirements will be managed by the branch. Angelo Ricci, president of the local host of the conference, FIAGOP, closed the official opening with a presentation of a survey about the commitment of parents' associations in Italy to support paediatric oncology and haematology.

Anja Nitzsche-Bell from the IAEA (International Atomic Energy Agency), talked about PACT, the International Program of Action for Cancer Therapy and future potential collaboration with CCI.



Other presenters were Olga on the recently started EU projects, in which CCI Europe is involved, namely JARC (Joint Action on Rare Cancers).

Closely linked with JARC and ExPO-r-Net (European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment) is the European Reference Network on Paediatric Cancer, the ERN PaedCan. Melanie Brunhofer from the Children's Cancer Research Institute in Vienna was on-site to present this visionary project; she is its network manager. Matt Johnson from EURORDIS, presented the European Patient Advocacy Groups (ePAGs) within European Reference Networks. There was also a presentation about the Survivorship-Passport (SUPA), After this presentation Riccardo Haupt had a workshop with survivors about this topic. Parallel to this workshop there were time slots for CCI members from Italy, Iceland and Turkey as well as Unite2Cure to present their projects and initiatives. The afternoon was characterised by program presentations, reaching from a European wide Retinoblastoma Awareness campaign to e-connected classrooms for cancer-sick children.

Sunday, May 14th 2017 – All good things must come to an end. The last conference day started with the presentation of Carina Schneider, Jaap den Hartogh and Aimilia Tsirou; they presented the outcomes of the two survivors' workshops of the last two days.

To strengthen the understanding of the European Reference Network on Paediatric Cancer amongst the participants and to get to know the expectations and wishes of parents and survivors in Europe in this regard there was an interactive session on Sunday. Within small working groups the following questions were answered:

- ERN PaedCan – What does it mean for you as a parent survivor? What are your expectations/wishes?
- What are your expectations/wishes to a national contact point?
- What are your expectations / wishes to CCI Europe?



In the afternoon, two parallel workshops took place. Felizitas Dunekamp and Anna Bürgi from Childhood Cancer Switzerland shared their expertise and experience regarding fundraising strategies for childhood cancer NGOs. The second very fruitful and productive workshop was for survivors only. Based on the motto "Survivors in Europe: Moving forward into a successful future" they shared concrete ideas how to create a European Network and also started to establish a steering committee.

We ended the day with the Market Place, where every organization/group could present itself.

Saturday, May 13th 2017 - Going into detail.

The next conference day had local initiatives presented by Franca Fagioli, president of AIEOP, the Italian Association of paediatric oncology, and Paola Quarello (AIEOP), who talked about a report about "Centralisation of diagnosis in paediatric oncology".

Martin Schrappe, SIOPE president, presented a very interesting and important study about international incidence of childhood cancer. We were not surprised that there are global variations but what we did not expect was that the incidence of childhood cancers neoplasms had increased substantially from 2001 to 2010, globally.

## E. Priority Advocacy Initiatives

### *The Paediatric Medicines Regulation*

The issuance of the Paediatric Medicines Regulation's 10-year report from the commission to the European parliament and the council triggered mixed feelings in the childhood cancer community.

On a positive note: The specific needs of children with cancer were recognized, the policy on deferrals will be reviewed to speed up access to innovation and the EU Commission wants to set up working groups on possible immediate improvements of the actual PMR.

BUT on a not so positive note: any amendments are deferred until 2019 and the implementation of waivers on basis of mechanism of action is seen as possibly impacting the predictability of the scope of PIP and a risk to the overall product development.



Thus, Unite2Cure wrote an open letter to the EU's Health Commissioner Vytenis Andriukaitis urging him to take action, pointing out a) the lack of access to innovative therapies for children; b) the truth about the childhood cancer cure rate, c) the long-term / late side effects, d) the loopholes in the actual regulation and all the missed opportunities to better cure childhood cancer.

Due to CCI's broad network and support and Unite2Cure's intense work, it was possible, in only a few days, to bring together signatures of support from 43 organisations in 20 European countries.

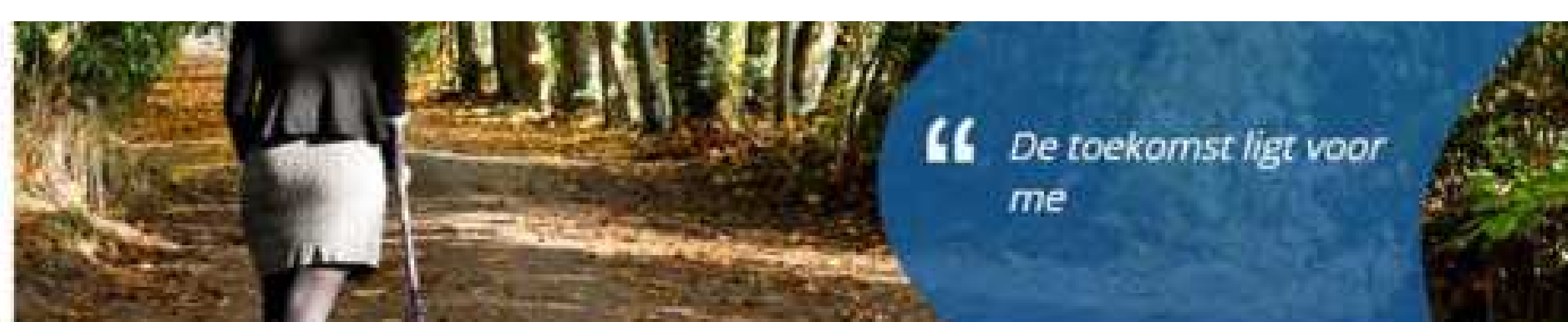
Commissioner Vytenis Andriukaitis promptly replied and admitted the deficiency of the Paediatric Medicines Regulation. He also assured the childhood cancer community that he is aware of the urgency, priority and necessity to drive developments and improvements forward and that he totally supports the concerns of the senders of the open letter.

**Prior to the release of the PMR's 10-year report, U2C created a book containing the pleas of survivors, parents and caregivers in regard to the PMR; this was gathered during the CCI Europe conference in Rome and was used as a material for advocacy at the EU parliament.**

## F. Innovative and significant activities of members

### 1. The Netherlands

#### The Netherlands



VOKK finished a two year project 'Improving support for families with a child with a brain tumor'. They developed quality criteria that were implemented in the Princess Máxima Centre and launched a digital reference guide for parents and health care providers.



VOKK launched the website [www.vox.nl](http://www.vox.nl) for adult survivors of childhood cancer. The website consists of two parts: one about long term follow-up, late effects and how to deal with them, one about what VOX, VOKK's survivors' department, is doing and offering. The site also offers stories of survivors.

VOKK launched a Support Fund for families with very limited financial resources.

### France

**U-Link: Improving access to the best treatment and care**

The U-Link project was launched by doctors, families and patients to fulfill the need for information about clinical trials in pediatric Oncology in France.

The availability of complete, understandable and updated information on clinical studies, as well as on their results after their closure is a legitimate demand of the public that has to be met

U-Link also includes a financial support program for travelling and hosting costs; lowering uncovered costs for the families is also a way to improve access both to routine care and to innovative drugs in clinical trials.

The idea of establishing a modern and accessible tool to meet these needs has emerged with U-Link, through a collaboration between the SFCE (French National Pediatric Oncology Society) and UNAPECLE (National Parent Organization Union).

The U-Link website (<http://www.u-link.eu>) was built to provide both doctors and families an information portal of quality, thanks to the collaboration of a group of specialists, social workers, parents and partners providing their experience related to their field of expertise.



The U-Link website gathers:

- A database that references all clinical trials in Oncology and Hematology Pediatric (children, adolescents and young adults) opened in France, with a double entry (which are both accessible):

One for physicians and healthcare professional public, providing a short summary of the trial design, objectives and inclusion criteria.

One for patients and their families with the most accessible language possible provided by members of UNAPECLE involved in the "informed consent reader group".

This database will also provide information about the results of the trials and clinical studies.

- Information on pediatric cancers, about treatment as well as answers to questions that families arise. These information are developed by specialists of the field and also written by members of parents organizations.

- A dedicated access for social workers of the treatment centers to ask for a financial support for travelling and hosting costs, action carried by the UNAPECLE for many years. A partnership program for free access to travel and hosting services is also included in that part of the project.



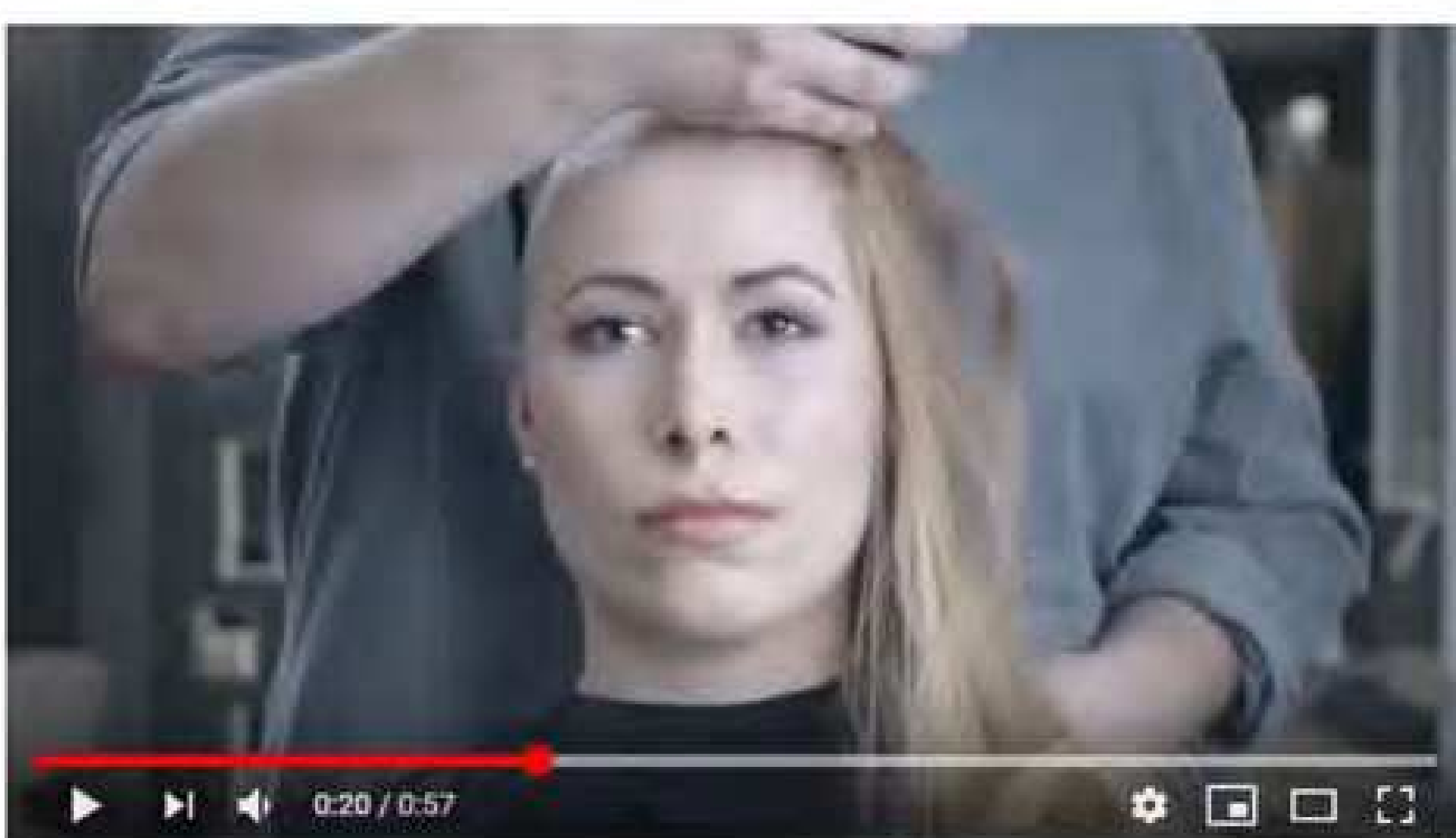
## Switzerland

Childhood Cancer Switzerland: Successful awareness campaign «**4 out of 5**» in September 2017

In September 2017, Childhood Cancer Awareness month, Switzerland launched its first awareness campaign: "4outof5". During that month, various print and digital media published articles about the campaign and Childhood Cancer Switzerland themselves used its Facebook, Twitter and YouTube channels to call for solidarity and support for the campaign.

The center of the campaign consisted of a video, showing a mother having her head shaved in solidarity with her child who has cancer. Furthermore, the title of the campaign, "4outof5", aimed at informing the public that more than 80% of children with cancer now survive 5 years or more.

Overall, the campaign and the video met with a positive and high impact response. More than 60 000 people watched the video and the number of CC Switzerland's Facebook Fans increased by 20%.



<https://www.youtube.com/watch?v=DHqT3ZI7KMA>

## Portugal

### “Dreaming with Survivors”: The Voice of Childhood Cancer Survivors

In general, youngsters have a little or non-existent involvement in the definition of public policies.

However involving young people is the best way to identify their own problems and needs, develop the adequate research about solutions and then fight for them.

Following this idea Dreaming with Survivors was launched by Acreditar (Portuguese parents organization that also supports Survivors). The first aim of this project was the creation of a Portuguese pediatric cancer survivors network to debate which would be the main changes that needed to be done for pediatric oncology.

As a result of the work developed so far the group nominated 8 spokespersons that together with specialists of each area are currently developing four different projects that correspond to the main priorities identified, thus far.

## A. The Survivorship Passport

Portuguese survivors think that it's crucial for them to have information about their own disease and a better long term follow up care. Thus, they need to define which are the required steps to achieve this important tool or to obtain the same gains through an alternative.

## B. Life and Health Insurance

The real possibility to have a life or health insurance has been made difficult, or impossible, to some survivors. Based on this findings, a survey has been launched to find out about quantitative and qualitative situations.

Once the concrete data is properly analyzed, the idea is to pressure the insurance market to make available appropriate insurance packages.

## C. Caring for Caregivers

Most Survivors think that their families have been "forgotten" during the treatments. So they decided to make a research about the real impact of childhood cancer in families so that at next phase they can address the solutions.

## D. Awareness in Schools

Survivors feel that the lack of knowledge both from professors and peers is creating barriers in regard to good integration at school. The group decided to develop, alongside with a company specialized in this field, a game that will be distributed in school to raise the needed awareness about pediatric cancer.

Next September, survivors will present the results of their work in these four areas and the development projects for next year.

This has been a very important step for this social mobilization movement to promote the rights and interests of pediatric cancer survivors and also contribute for Acreditar accomplishment of its mission.

## Spain

In the Federación Española de Padres de NIÑOS CON CÁNCER, we are working to obtain the granting of 33% disability to children and adolescents with cancer from the moment of diagnosis.

Children suffering from this disease face a situation of disadvantage that is included in the definition of disability proposed by the World Health Organization.

More than a year ago, our organization met our historic demand of 33% disability, when we obtained the approval of a second Non-Legislative Motion -the first one approved on Dec. 20th 2016- by the Health and Social Services Commission of the Congress of Deputies. But our struggle does not end there, since current state regulations don't consider yet the disability at the moment of diagnosis

**Working together,  
we create lasting,  
positive changes  
for kids with  
cancer.**







From that day on, all activities of daily life such as going to school, playing or interacting with other children are interrupted, and in most cases, this period lasts from 1 to 2 years. Therefore, waiting 6 months or at the end of treatment for the disability to be granted doesn't meet the needs of this group, and deprives children and their families of access to services and benefits to which they are entitled.

That's why our organization got down to work last summer by launching our "#Dales33%" campaign, which aims to reach out to society through social networks to raise awareness and support. And it has been a great success.

After the campaign ended, there were a total of 43 media appearances - including EFE and Servimedia, and some of the most important national newspapers such as La Vanguardia, El Confidencial, ABC, 20 Minutos and La Información – 75.300 posts on Twitter and 213.500 posts on Facebook.

"Time is your hope. Don't make them wait", "They count on for you, make every second count" or "We can ask for it in many ways, but we can only live it in one", are some of the messages that we echoed in the virtual community.

***“We can ask for it in many ways, but we can only live it in one”***

In this way, we requested a legislative amendment to Royal Decree 1971/1999, Dec. 23rd, 1999, on the procedure for the recognition, declaration and qualification of the degree of disability, incorporating in Chapter 11, corresponding to neoplasms, a section that includes the mandatory recognition of 33% of disability to patients aged 0 to 18 diagnosed with cancer from the very moment of the diagnosis.

We can't wait any longer, we've insisted. Specific indications for the concession, homogeneous criteria in all the Autonomous Communities and non-face to face disability evaluations are some of the advantages that could help these children and adolescents and their families to cope with this illness in which time plays a key role.

### **Other significant new alliances or collaborative partnerships**

WECAN (Workgroup of European Cancer Patient Advocacy Networks)



Due to the lack of personnel capacities CCI-E ReC decided to stay in an observer role. Attendance of meetings if possible.



Since 2017, CCI Europe collaborates with the pharmaceutical company Shire. This means on the one hand financial support for specific projects and on the other hand advisory activities. During the CCI Europe Regional conference in Rome, the CCI Europe Regional Committee had a very fruitful meeting with Mary Uhlenhopp, Director, Global Advocacy, Oncology & Immunology at Shire, where she counseled the committee in regard to collaborations with industry including pharma companies. Later in 2017, ensuing to the CCI/SIOP conference in October in Washington, Shire invited CCI Europe (Anita Kienesberger, Luisa Basset, Carina Schneider, Holly Wattwil, Nicole Scobie, Mary Claire Rennick, Stephanie Schremmer) for an Acute Lymphoblastic Leukaemia Patient Advocacy Group Roundtable Meeting where they asked for the patient's input and patient's needs. CCI Europe is looking forward to further collaborate with Shire as well as other pharmaceutical companies in the future.

# CCI EUROPE: STRONGER TOGETHER!





# CHILDHOOD CANCER INTERNATIONAL AFRICA

## Hope for kids with cancer

### AFRICA

#### 4th Childhood Cancer International Africa Regional Conference

The 4th Childhood Cancer International Africa Regional Conference was held simultaneously with the 12th Continental Meeting of the International Society of Pediatric Oncology (SIOP), in the beautiful city of Marrakesh, Morocco on 5-8 April. Organized by SIOP (headed by Professor Lorna Renner) and CCI in collaboration with the Moroccan Society of Pediatric Hematology and Oncology (SMHOP), the meeting was a great opportunity for 200 representatives of the Pediatric Oncology Community from French speaking Africa and nearby countries in Africa and Europe, to meet, share their experiences and discuss solutions to issues facing access to care in Africa.



The conference objectives were:

- a) Advocate globally on behalf of patients and families for access to the art of diagnosis, treatment and care for every child and adolescent with cancer,
- b) Provide training opportunities for all childhood and adolescent cancer care providers worldwide on the latest clinical and scientific advances through meetings, networking and educational outreach for continuing professional development,
- c) Promote and advance basic, clinical and other research by supporting collaborative opportunities and translating scientific discovery to improve the outcomes for children and adolescents with cancer,
- d) Support those caring for children and adolescents with cancer and provide them the best curative and palliative therapies and
- e) Advocate for appropriate long-term follow up for survivors  
The program covered pediatric oncology care in African countries and included separate parents and nurses track.

The CCI Parent Track had a keynote presentation on Pediatric Palliative Care: A people centered approach by Dr. Maries-Charlotte Bouesseau, WHO HQ Advisor for Service Delivery and Safety. It also had organizational development related presentations from CCI anchor organization, CHOC South Africa ( Carl Querios; From Good to Great – Building Capacity and Sustainability), CCI founding member , Prof. Fouzia Msefer Alaoui (The Avenir Association :30 years supporting children with cancer in Morocco), Parent Support Associations : What They Do in Groupe Franco-Africain d'Oncologie Pediatrique (GFAOP) . The value of volunteers and volunteerism was also highlighted and encouraged through presentations from Lalla Salma, LAvenir, Rwanda Childrens Cancer Relief (RCCR), and Botswana Parents Group who shared the roles and contributions of volunteers in caring for children affected by cancer as well as in awareness building activities.

CHOC provided support for 20 local attendees of CCI member organizations in Marrakech to join the conference. It also hosted a networking dinner for CCI participants, colleagues from SIOP and GFAOP and the CCI Board Members.

## OVERCOME THROUGH COURAGE & STRENGTH





## ACTIVITIES CARRIED OUT

### A. Kids Cancer Walk

Kid's Cancer Walk is the main activity of the RCCR childhood cancer awareness month. It gathered participants from all the walks of life.

The walk started from the National Institute of Statistics of Rwanda to Kigali car free zone where it was followed by a number of activities notably.

- Testimonials from cancer survivors,
- Informative session from pediatric oncologists,
- A talk from partners coordinated by our gold sponsor I&M bank that emphasized on the role of private sector to advance the global health equity.
- The fundraising event for Sheja, a 4-year-old kid who had a brain tumor. More than 600 participants attended the work and more than 1,000 informative flyers and posters were distributed. The walk was covered by 5 local radios, 4 local news papers and 1 television.

### B. Conducting awareness talks in media (live chats on social media, radio talks)

Media talks were mainly designed to reach out to the whole population of the country. Talks were composed of radio talks, social media talks and newspaper interviews. The September month featured in 1 radio talk show, 5 live chats on Facebook and Twitter, and 4 articles in newspapers.

Media talks had a great impact in terms of reaching out to a large audience which was measured in a great number of shared posts and feedback from the population.



### C. 4th RCCR Childhood Cancer Awareness Month

As September is Worldwide Cancer Awareness month, every year RCCR stands with the community to raise awareness on Childhood Cancers. This includes the types of cancer that affect kids, education and sensitization about signs and symptoms, preventive measures and treatment guidance and advocate for better treatments.

From August 26th to the 30th of September 2017, Rwanda Childhood Cancer Relief joined the rest of the world for the Childhood Cancer Awareness month.

The childhood cancer awareness month was conducted in close collaboration with our undeniable partners I&M Bank, DANA FARBER Cancer Institute, RBC and Kaygraphix.

### D. Trainings and capacity building for health centers







## THE RCCR AWARENESS MONTH

### Advocacy for Sheja

RCCR in its mission advocates for children affected by cancer to access better treatments. With the support from our partners, RCCR advocated for Sheja, a 4-year-old kid who had a brain tumor but couldn't afford treatment.

The kid was successfully operated in India at Apollo Hospitals.



### Umuganda (August 26th 2017)

Conducted in the southern province of Rwanda, Kamonyi district alongside our partners (I&M bank) and a good number of RCCR volunteers, we joined residents of Nyagacyamu village, Muganza cell, Runda Sector (commonly known as RUYENZI) to make a road that reaches to the sector's primary school.

After that activity, we conducted a 30-minute teaching session about childhood cancers, then took part in the community discussion. This marked the starting point of RCCR Monthly activities.

A summary of the impact in numbers and attendees:

**Government presence:** The governor of the southern province, vice-mayor Kamonyi district and a number of local authorities, police and the army.

**Attendance:** With a maximum number of 700 people all around Runda sector and neighboring sectors.

**Medias and Social Media:** Igihe.com and Rwanda Broadcasting Agency.

Generally, during outreaches more than 1,000 population were reached and 90 healthcare providers from 4 health centers and 50 community health workers were trained on childhood cancer.



### Outreaches

During September, outreaches focus on trainings and informative sessions. Trainings are designed for health care providers at the level of health centers. Targeting health care providers was to enhance an early detection of signs and symptoms of cancer since they are the first to meet patients.

Informative sessions were designed for the general population with the aim of promoting preventive measures, treatment guidance and raising awareness.

- Outreaches were carried out in:
1. KAMONYI HEALTH CENTER (September 11, 2017)
  2. KINYINYA HEALTH CENTER (September 14, 2017)
  3. MASAKA HEALTH CENTER (September 15, 2017)
  4. KABUGA HEALTH CENTER (September 17, 2017)

Generally, during outreaches more than 1000 population were reached and 90 healthcare providers from 4 health centers were trained.





## Closing Community Work (Umuganda) September 30, 2017



Umuganda at Rilima marked the end of RCCR childhood cancer awareness month. RCCR volunteers joined the population of Rilima to clean the road and its surrounding. After Umuganda activities, residents of Rilima including the population and community health workers had a one hour informative session that mainly focused on childhood cancers and the program of vaccinating young girls from the cervical cancer. Over 100 population of Rilima benefited from this activity.

## Results and Outcomes

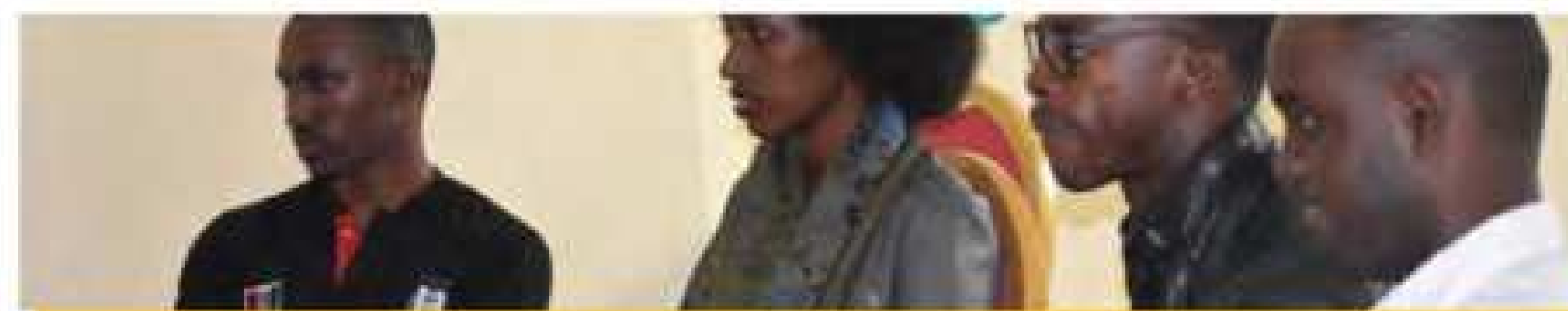
- A 100 plus health care providers were trained and educated about childhood cancers. This is to enhance an early detection, promote early treatment and seek for support when needed.
- Following the walk and public sensitization, the population got insights on signs and symptoms about kids' cancer. This will eradicate the myths and past perception about cancers.
- With a radio talk show and the trend on social media, the campaign was conducted countrywide, which stimulated people's curiosity; people are getting aware of childhood cancers.
- The role of the private sector in health was more highlighted with our partners. This gives many chances to a more involvement of the private sector in health related issues.

## Pediatric Christmas event



Christmas being a joyful day to many of us, at RCCR we always think about our beneficiaries. Therefore the Pediatric Christmas event was organized to bring hope and wish a happy New Year to children battling with cancer on beds. On December 30th 2017, RCCR with partners visited children in Kigali Teaching University Hospital to celebrate Christmas and the New Year with their families.

## RCCR General staff meeting



The general staff meeting is an annual gathering that aims at revising the year and forging the way forward. During the gathering, best volunteers are awarded and recognized for a tremendous work. The annual gathering serves as a planning meeting for the next year action plan

## A healing voice from our champion



### Karen Busingo

*What doesn't kill you surely makes you stronger. It's been 5 years now since I survived Cancer but every day of my life is an exciting chapter that opens up because of the tough fight I fought. It left me wiser and stronger, If you are out there fighting Cancer know that the best is ahead and one day you will look back and be proud of yourself as you inspire many around you. if I did it, you can too Stay strong and many blessings.*



## KENYA

### Hope for Cancer Kids.

**2017 was a successful year full of exciting activities and significant milestones for HCK.**

#### **February World Cancer Day and ICCD**

Together with the Kenya Network of Cancer Organizations (KENCO) and Kenyans, HCK participated in the 4th February World Cancer Day which was held in front of the Kenya Archives in the Nairobi town center.

International Childhood Cancer Day 2017 started early and lasted the whole month of February; HCK held a Valentine's Funds Drive campaign on social media. On ICCD itself, 15th February, HCK disseminated Childhood Cancer Infographs from the Childhood Cancer International to share with the Kenyan people basic and graphic information on childhood cancers. This saw HCK attract the attention of many people on Facebook leading to increased knowledge about childhood cancer, the organization and what it does. HCK got to create increased awareness and advocacy for support to children with cancer through Television interviews on major TV networks: KBC and NTV.



#### **Childrens Walk and School Focused Awareness Raising**

On 26th May, HCK held a children's walk where families and friends of children and adolescents with Cancer, walked to show support and a united front against childhood cancer in Kenya. Students from several private and international Schools participated.

During the walk preparation period, the HCK team did a childhood cancer awareness day visit at the Braeburn Imani School in Thika. The school administration organized a class by class and general school sessions with the HCK team; students and their teachers were educated by a pediatric oncologist, nutritionist, palliative care giver and HCK about cancer in children and adolescents. The successful and enlightening event ended with many students supporting children with cancer through purchasing the HCK walk merchandise. The outcome of this event was to develop and continue a similar program in interested schools and churches starting with Nairobi County.

#### **Organizational Strengthening**

HCK together with other KENCO members participated in the American Cancer Society training and technical assistance program for developing organizations working in the cancer field

This program is called the SOURCE program (Strengthening Organizations towards a United Response to the Cancer Epidemic). The program was finalized by a Financial Sustainability practicum where HCK developed a proposal to secure a small grant from ACS for developing and publishing an HCK newsletter aimed at creating awareness on childhood cancer.

#### **HCK also continued with the implementation of its treatment support program to the children through the National Hospital Insurance Fund**

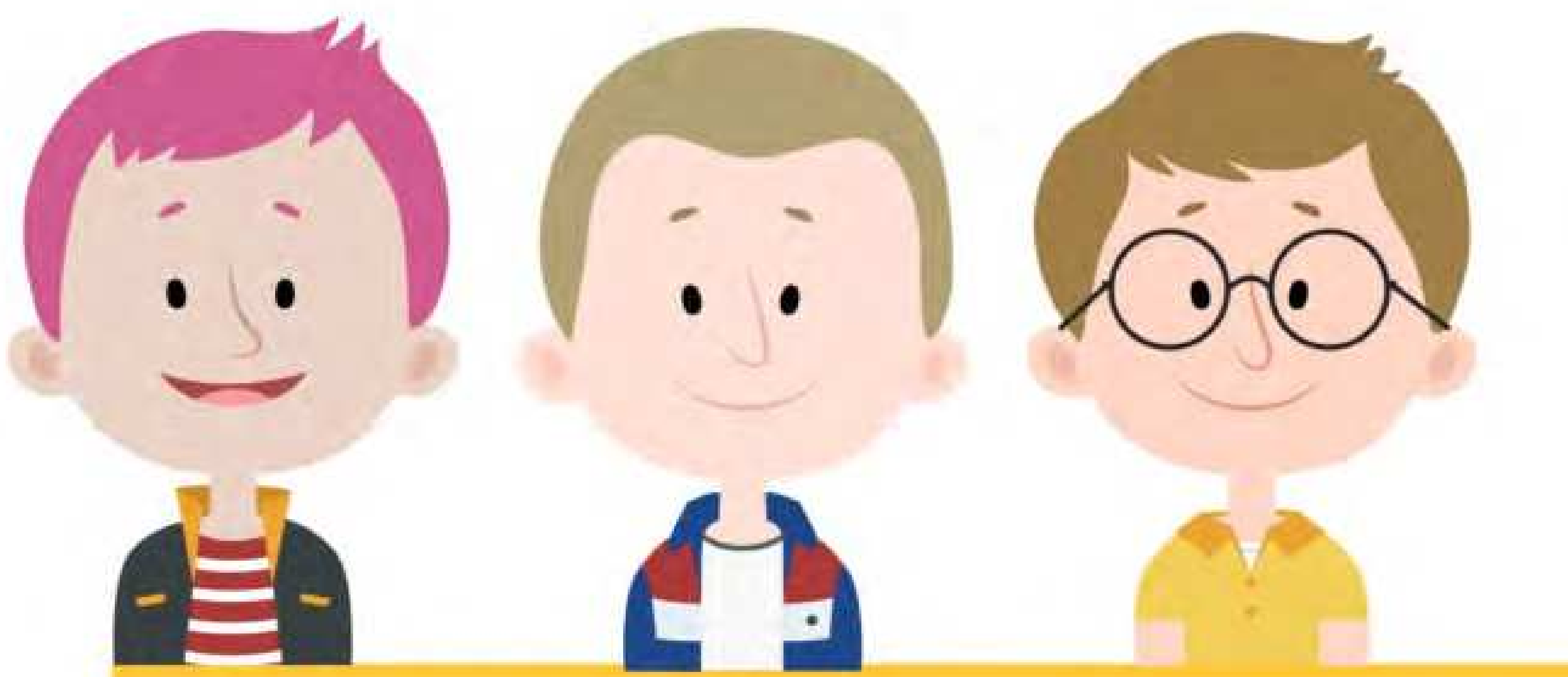
Support mostly went to children receiving treatment at the Kenyatta National Hospital (KNH) and Moi Teaching and Referral Hospital (MTRH) with a few from Jaramogi Oginga Odinga Teaching and Referral Hospital, Kisii Level 5 and Coast Provincial General Hospital.

From January 2016 to December 2017, HCK has supported 392 children with the NHIF support program. Initially, the insurance covered full treatment for the children but that has since changed with the introduction of changes that limit this full cover. HCK together with KENCO have raised these concerns with the government insurance provider.

**BRING SMILES,  
JOY, and HOPE!**







## ZAMBIA

**The following awareness activities and fundraising events were undertaken by the Kajula Childhood Cancer Foundation which supports the childhood cancer community based at the cancer diseases hospital in Lusaka**

### 1. **International Childhood Cancer Day (ICCD)**

2017 was commemorated by KCCF through week long high impact special events .

On 15th February 2017, the ICCD awareness programme took place at the Munali Special School for the hearing impaired and the Chainama Hills Hospital Special School in Lusaka Zambia.

On 14th and 17th February , Executive Director Mrs Victoria Silu-tongwe had radio interviews to increase awareness on childhood cancer , highlight the work the foundation is doing and appeal to listeners for support .

On 18th February, a Drama and Musical Concert was held with the Republic of Zambia's First Lady, Mrs. Esther Lungu as the guest of honour.

### 2. **International Survivors Week (Month)**

It was celebrated through the Gold Ribbon Aerobics Mania for Kids with Cancer was held on 3rd June 2017 from 06: 30 hours to 09:00 hours at East Park Mall, Lusaka Zambia. The theme of the event was "Together for Kids with Cancer" . The Foundation partnered with Mr. Muyembe Makungo, an aerobics instructor. The participants were individuals and representatives from various companies who paid an entry fee to participate.

In addition from June 22-24, the Parent House premises was given a face lift through partnership with the Sam Damalis Trust Fund (SDTF), Micmar Zambia, Dulux Zambia Limited and Build It International Zambia who did the kick-off

### 3. **International Childhood Cancer Awareness Month**

kickEd off with a Football Tournament held on Saturday 9th September. Corporate teams were invited to compete and paid an entry fee to participate.

### 4. **PwC's Race to Beat Cancer**

Cancer raised K 102,000.00 for the Kayula Childhood Cancer Foundation . The funds were raised from 542 runners who took part in the race and represented an increase of K 42,000.00 over the amount of K 60,000.00 raised in 2016. Mr. Andrew Chibuye, a partner at PwC stated that PwC was proud of the efforts that KCCF was making to assist families and children who came from far and wide to receive treatment at the country's only Cancer treatment facility. He encouraged other corporates and well-wishers to come forward and support the Foundation.

## A. **Groundbreaking advocacy initiatives**

### **South Africa**

CHOC SA is a member of the Cancer Alliance (CA) which has a paediatric oncology representative, Dr Jennifer Geel, on the Ministerial Advisory Cancer Committee (MACC) which assists and advises the Minister of Health on cancer issues in SA.

The SA National Cancer Control Policy has been accepted. Nevertheless, a National Cancer Control Plan for children is also being developed.

Together with Cancer Alliance and Section 27, CHOC advocates for addressing Childhood cancer medicine stock outs and ensuring availability of Childhood cancer essential medicine. It also facilitated and assists children with cancer to access specialised treatment centers in SA.

The National Health Council has approved a Policy Framework and Strategy for Palliative Care for South Africa. Choc together with members of the Cancer Alliance are currently putting together a toolkit for patients to know / be informed of their rights.

Carl Queiros is on the National Department of Health task team for a national cancer awareness campaign in SA while Adri Ludick represents childhood cancer on the national task team to write Cancer Survivor Strategy.



## 2. Ghana

The Ghana Parents Group successfully advocated and mobilized resources for a Multi story, Multi purpose building to be used as transient family home , venue for conferences , trainings and meetings .

Kumasi has been selected by UICC as one of its pilot cities for its CCan project .



## 3. International Childhood Cancer Awareness Month

The event kicked-off with a Football-Tournament on Saturday 9th September. Corporate teams were invited to compete and paid an entry fee to participate.

## B. Capacity Development Initiatives

We also met the Cancer Task Team and other stakeholders at the Swaziland National Aid Programme office in Mbabane. 24 Stakeholders from the Ministry of Health and other NGOs attended the meeting and was very interested in CHOC's training programme.

Bongiwe Dlamini (Snr Health Education Programme Officer MOH), Dr Lukhule (Director Child Health MOH), Adri Ludick, Denise Mortlock, Makhosazana Hlatshwayo (Executive Director Baylor College of Medicine Children's Foundation Swaziland), Carl Queiros

In October 2017 CHOC trained 217 Swaziland National Pediatric Aids Programme Trainers, Paediatricians, Doctors and Nurses from Government Hospitals, NGOs and Baylor College Baylor College, Mbabane. Trainees represented all the regions in Swaziland namely the Manzini, Hhohho, Shiselweni and Lubombo regions. Dr Gita Naidu (Paediatric Oncologist and subject matter expert on childhood cancers and life-threatening blood disorders from SA) joined CHOC and assisted with the training.

## 4. PwC's Race to Beat Cancer

Cancer raised K 102,000.00 for the Kayula Childhood Cancer Foundation . The funds were raised from 542 runners who took part in the race and represented an increase of K 42,000.00 over the amount of K 60,000.00 raised in 2016. Mr. Andrew Chibuye, a partner at PwC stated that PwC was proud of the efforts that KCCF was making to assist families and children who came from far and wide to receive treatment at the country's only Cancer treatment facility. He encouraged other corporates and well-wishers to come forward and support the Foundation.





## A. ICCD : intensifying Awareness and Generating Mileage

South Africa had yet another very successful International Childhood Cancer Day (ICCD) . We continued with our “Have a heart for children with cancer” campaign, which generated great awareness for childhood cancer and facilitated fundraising for CHOC. During this campaign, tremendous publicity was achieved ; we sold thousands of specially designed badges, heart pins and heart-shaped chocolates to schools, corporates, religious groups and individuals; various initiatives were held by our offices country wide.

Our greatest achievement was a social media based campaign for the General Public supported by a nationwide retail store (Westpack) . They gave out vouchers as people tagged us in their ICCD photos and local celebrities over and above our ambassadors got involved, posting information about ICCD on their social media pages such as the SABC news anchors, Basetsana Khumalo, The Blue Bulls and Suzelle DIY amongst others.

Intense media mileage was gained from the CHOC ICCD adverts that aired on all radio stations and Television channels of the South Africa Broadcasting Corporation (SABC) to the value of over a million at no cost to CHOC. Advert link- <https://www.youtube.com/watch?v=vzWjFdagVp4>



Media interviews unpacking the early warning signs of childhood cancer were conducted with well known radio stations in various South African languages along with TV interviews. The ICCD Press Release received great print exposure to a total of 57 newspapers to A.V.E of R832, 334 that consisted of the The Star, Cape Argus, Cape Times, daily dispatch, Sowetan- regionally, Beeld to name a few. We also received coverage in the Child Magazine. Online Media included Media update, Mix FM website, IOL site, City Buzz, Algoa cares site, The regions hosted various awareness activations nationwide and reaching schools, corporates, hospitals, clinics and Malls. Attached are some photos to show the experience.



## D. Scaling up Community outreach through Training. Public Health Education and Materials Development

Since CHOC started the Awareness Programme (Training and Education) in SA we have trained over 22041 Healthcare Professionals, Healthcare Workers and African Traditional Practitioners on the Early Warning Signs of childhood cancer, disease knowledge and how to demystify the stigma and beliefs around the disease.

We developed an excellent training programme with learning packages and toolkits to fit each strategy.

CHOC in partnership with Campaigning for Cancer launched a pilot programme in one of the nine provinces in SA and have done our first successful community outreach where we also launched the campaign, Vuka Khuluma – the vernacular as opposed to “Wake up and Talk”

## E. Networking and Collaborative Partnerships



During 2016 CHOC launched the Childhood Cancer Network. The network is a multi-stakeholder group of organisations that engage in childhood cancer care and control in South Africa, brought together to establish a network that seeks to collaborate, co-ordinate and advocate on behalf of childhood cancer and life threatening blood disorders (LTBD) in South Africa. Since the start the network has grown and positive collaboration between the organisations was formed.

CHOC belongs to and works with several alliances in SA to advocate for children with cancer. We are part of the Cancer Alliance SA, The NCD SA Alliance, The Alliance for Access to Palliative Care and Section 27. We work closely with the South African Childhood Cancer Study Group in SA for technical advice on childhood cancer, life-threatening blood disorders and NCD's.



## ETHIOPIA

### News of Pediatric Cancer Consultative Meeting

Considering that childhood cancer is becoming a public health problem in developing countries like Ethiopia, FMOH in collaboration with MWECS held a fruitful & productive consultative meeting on Pediatrics Cancer from March 3-4, 2017. There were 21 participants on the consultative meeting. The participants were from Regional Universities of Ethiopia, Black Lion Hospital Oncology Department, CSOs, FMOH and International Partners (ASLAN Project).

Mr. Wondu Bekele, General Manager of Mathiwos Wondu-YeEthiopia Cancer Society officially welcomed participants. The Consultative meeting was officially opened by Dr. Kunuz Abdela, Technical Advisor of NCCP, Federal Ministry of Health/FMOH/ who showed the effect of childhood cancer and the effort being made to encourage early detection & cure mechanisms that have to be taken towards the problem. Following the Opening speech of Dr. Kunuz, Dr. Molla Gedefaw, NCD Focal Person of FMOH briefly showed the progress being made to challenge the growing NCD burden in Ethiopia



### Some of the Pediatric Cancer Consultative Meeting Participants posed for the photo

Dr. Daniel Hailu, Pediatric Oncologist, from Black Lion Hospital Pediatric Hematology & Oncology Unit, momentarily described the challenges of pediatric oncology from Ethiopian perspectives. Following him participants from regional universities medical schools shared their challenges & prospective, CSOs and International partners shared their side of experience including the main challenges on childhood cancer respective of where they came from.

Dr. Daniel Hailu, Pediatric Oncologist, from Black Lion Hospital Pediatric Hematology & Oncology Unit, momentarily described the challenges of pediatric oncology from Ethiopian perspectives. Following him participants from regional universities medical schools shared their challenges & prospective, CSOs and International partners shared their side of experience including the main challenges on childhood cancer respective of where they came from.

The consultative meeting was concluded by establishing a working task force to develop action plan for pediatric cancer intended to decrease the suffering of pediatric cancer patients & increase their survival rate. Dr. Kassu Ketema, the newly appointed Director of Diseases Prevention & Control Directorate of FMOH joined the meeting & presented closing remarks. He assured the participants the commitment of the ministry to make every possible effort to support the working task force to develop action plan on how to challenge the growing childhood cancer in Ethiopia.

On behalf of our society, Mathiwos Wondu-YeEthiopia Cancer Society & its partners, we would like to sincerely thank American Academy of Pediatrics/AAP/ for their generous financial & technical support from their NCDChild advocacy in action mini grant for making this long awaited consultative meeting a reality.



# STORIES OF HOPE

## SOUTH AFRICA

### Romina Armellini

Born in Johannesburg South Africa, like most swimmers I started swimming at a young age. I had a progressive and successful junior career until the age of 17 years - a point where I was ranked 2nd globally in my event/age group and already competing in finals at World Grand Prix contests. It was at this point in my athletic career where my potential was just starting to show.

On a routine visit to my GP due to flu, my life changed from being an athlete to being that of a patient. I was sent immediately for further testing and investigation into swollen glands around my throat. Five days later I was diagnosed with stage 2 thyroid cancer. Two days after the diagnosis I was on the operating table scheduled for the removal of my thyroid. However once in theatre, it was discovered that the cancer was not in stage 2 but stage 4. After a ten hours of operation I no longer had a thyroid, 3 parathyroids or a piece of my back muscle. In addition, the surgeon had to scrape pieces of cancer off my lungs. One of the hardest things about cancer is the endless trips to and from the hospital for constant treatments and controls. My story was no different to other cancer patients. I underwent radiation therapy a few times with increasing intensity until they found that the cancer had spread to the liver as well. At this point (5 months after the first diagnosis) it was estimated that I had a 20% chance of surviving. At this point I had chosen to stop treatment and enjoy my quality of life on a day-to-day basis. A month later I went for a control scan and the doctors were shocked to find that the cancer had completely disappeared. All were in shock except for me because while I was going through this whole experience I continued to swim (even though doctors said it was physically impossible) but in a completely different way. I no longer swam for the medals; I swam for the love of the water and felt the miracle that exists behind every breath. Living in this way I no longer feared death.



My love and passion for sport gave me discipline and taught me how to believe even against the odds. I continued swimming in this way; moved to Italy (as I was offered sponsorship opportunities) and managed to achieve many of my dreams: University Games, European Championships, World Championships and Olympics in 2008. Since 2009 I have retired as a swimmer and worked as a life coach and motivator as well as volunteering on many projects that better the lives of those involved with cancer in Italy: I have two Guinness world records (2009 and 2012) for the longest continuous swim relay and I was a spokesperson (2008-2012) for "Citta delle Speranze" (City of Hope) - a paediatric hospital specialising in treatment for cancer in Padova, Italy. Now back in my country of birth. I intend to continue sharing hope through being an example and sharing the lessons that I have learnt. It is for this reason that I contacted CHOC, who have graciously opened their doors to me.

### Dr. Nonkululeko Mthembu



In 1995 I was diagnosed with a germ cell tumour of the ovaries. I was 14 years old and it all felt like it was all a bad dream. Chemotherapy was tough but I was determined to live a normal life despite the cancer. I continued with school and my schoolmates were supportive and a little curious at times. After 6 months of chemo sessions and surgery, I was on the road to recovery. I miraculously passed grade 9 and received an unexpected award at school for extraordinary academic performance. That still brings tears to my eyes. Today I am a qualified medical doctor, graduated from Wits University. I am currently completing my Fellowship in Public Health Medicine and working at Charlotte Maxeke Johannesburg Academic Hospital. There is life after cancer and I am grateful to the dedicated staff at CHOC for their commitment to the saving lives of children with cancer.



# CHILDHOOD CANCER INTERNATIONAL NORTH AMERICA

## 📍 AMERICA

### Kids with cancer society,

#### North Alberta

*With a membership of more than 2,000 and the provision of more than 50 free programs and services The Kids with Cancer Society of Northern Alberta (KWCS) continues to serve children with cancer and their families who reside in Northern Alberta and the North West Territories of Canada.*

#### In 2017 several major projects were initiated:

- As 40% of our membership reside in rural areas, we purchased land to construct a small short term accommodation facility "Papa Ken's House" for families who are required to travel to Edmonton for treatment and follow-up. (This follows a successful pilot project which provided hotel accommodation since 2015 to determine the feasibility of constructing a stand-alone facility).
- A three year grant to the hospital that will enable more children to access clinical trials.
- The creation of a survivors program that will address the psychosocial, education, and life skill programs to assist this population.
- Increased awareness program that will focus on increasing pediatric oncology research dollars.



#### A summary of programs and support provided during 2017

- Financial support was provided to 685 families, including daily living funding, medical funding (ie prescription co-payment), palliative and burial support. This support is provided through referral by the Kids with Cancer Society social worker.
- Programs and services were accessed more than 2500 times which included participation at events, cancer in the classroom programs, drop in support groups, school transition programs, counselling services, scholarships, camps, bereavement groups and assistive technology support.
- 130 families were provided with overnight accommodation.
- Ongoing assessment of individual patient and family needs. This support is provided to families at the time of diagnosis, through treatment, palliation and bereavement. The end goal is to ensure that all families are aware of our services that they may access.

**Childhood cancer research is vastly and consistently underfunded.**



In an effort to further expand and enhance our services and identify program gaps, we are currently embarking on a needs assessment.

This will include focus groups targeting families at all stages of treatment, as well as survivors and those with long term effects of treatment.

Following the needs assessment, a five year strategic plan will be created to address any emerging issues.



# STORIES OF HOPE

## Joshua's freedom



### AMERICA

***He knows he's not athletic, so he holds back. He's reluctant to try. But at PEER, he's free to be himself. He can just be a kid without being different.***

***— Michael, Joshua's father***

***When Joshua watched *The Greatest Showman*, the tears streamed down his cheeks. His mom believes he felt a connection with the outsiders in the movie because he feels different too.***

Maybe the tears came because he was being bullied at school. A secret that only he and his tormentors knew.

Josh walks with a limp and fatigues easily. The boys at school tease him because he can't keep up. They taunt him as they lap him in gym class, whispering that he's a baby and he's lazy.

None of this is Josh's fault. But he lives with the painful reality of it every day. It is the fall-out of cancer treatments he received when he was five.

One day, last September, Josh was having an especially bad day. It was the first day of PEER

program with more weekly sessions. This enabled Josh to go for the first time.

Josh is like many childhood cancer survivors, who fall behind their peers in motor development because invasive medical procedures, treatment-related isolation and permanent side effects make regular activity difficult. "I know Josh needs to be challenged," his father Michael says. "But his teachers need to recognize that he has limits and they're different limits than his peers. PEER is a safe place where Josh can be challenged and have fun."

Josh is still terrified of his tormentors and only recently told his parents about the teasing – after months of sitting alone at lunchtime and on the sidelines at recess.

His parents still don't know for sure that the bullying has stopped, even though they've had a serious sit-down with his teachers. Next year, he's going to a different school.

Thankfully, Josh now has PEER to help him through this painful time.

"He's a different kid at PEER," his father says. "He walks in like he owns the place. Even if he is sitting out in gym class, at least he has PEER every week."

To learn more about PEER, please [email Carolina](#).



# STORIES OF HOPE

 CANADA

## INTRODUCTORY TEXT FOR DIGITAL STORY

### A STORY OF HOPE

One of the hardest days in Ed's life was telling his son there were no treatment options left in his battle with cancer. "It's one of the most difficult discussions I had with Joel, figuring out how to tell him there was no more hope. But he didn't give up. He kept trying. That's why research is important. You can't give up."

Kids Cancer Care is partnering in a national research effort that was designed with kids like Joel in mind. It's called Terry Fox PROFYLE and it is the first time in Canadian history that more than 30 children's cancer research groups have joined forces to give kids like Joel a second chance.

***It's one of the most difficult discussions I had with Joel, figuring out how to tell him there was no more hope in his cancer battle. But he didn't give up. He kept trying. That's why research is important. You can't give up.***  
— Ed Zukowski



Joel Zukowski was 10 years old when he was diagnosed with medulloblastoma, a pediatric brain cancer. Just when they thought he was out of harm's way, Joel relapsed. He was 15 years old and had exhausted all treatment options. After a long, courageous fight, Joel passed away on October 3, 2015 at the age of 16.

No amount of research could have saved Joel after he relapsed, but his parents Ed and Dale Zukowski are still grateful to research. "We think about the day Joel was first diagnosed," says Dale. "What if there was no understanding of chemotherapy, or radiation or surgery at that time. If they didn't do research, Joel may not have made it more than six months after being diagnosed."

## kids cancer care

Kids Cancer Care is partnering in a new pan-Canadian research effort that was designed with kids like Joel in mind. It's called Terry Fox PROFYLE and it is the first time in Canadian history that more than 30 children's cancer research and funding groups have joined forces to give kids like Joel a second chance.

Short for PReCISION Oncology For Young People and spearheaded by the Terry Fox Research Institute (TFRI) in Vancouver, British Columbia, PROFYLE scientists are establishing molecular profiles of patient tumours that have resisted conventional therapies in order to identify new avenues for treatment.

Dr. David Malkin, based at Toronto's Hospital for Sick Children (SickKids) is the project lead. He says PROFYLE brings together the nation's entire pediatric and young adult clinical and research expertise to offer precision medicine in a way that has never before been offered in Canada.

University of Calgary clinician-researchers Dr. Victor Lewis and Dr. Jennifer Chan will co-lead the project in Calgary, Alberta. Lewis will help identify and treat patients, who may benefit from PROFYLE, while Chan oversees PROFYLE's national bio-bank.

As the nation's bio-bank lead, Chan will oversee the collection of and access to the right kind of tissue and fluid samples for research into treatment options. She is also developing nationwide protocols for bio-specimen collection and overseeing the clinical data repository, facilitated by the Clinical Research Unit at the Cumming School of Medicine.

"We now know brain cancers in adults are not the same cancers that develop in children," says Chan, who holds the Kids Cancer Care Chair in Pediatric Oncology Research. "We've learned that while the tumours may appear the same to the naked eye, and even under the microscope, at the molecular level, they are very different, and that means we need to develop new treatment protocols for kids."

As the Kids Cancer Care Chair in Oncology Research, Chan's lab is supported by financial investments from the Alberta Children's Hospital Foundation and the Kids Cancer Care Foundation of Alberta.

"We are thrilled to see the Terry Fox PROFYLE initiative come to life," says Christine McIver, Founder and Chief Executive Officer of Kids Cancer Care. "If we are going to make any progress in treating incurable children's cancers, we need collaboration at all levels of society – government, industry, universities, hospitals, charitable organizations, individual and corporate philanthropists. PROFYLE is that collaboration and will bring hope to Canadian families who currently have no hope for a cure. We're so grateful to our generous community for making this possible."





CANADA



In 2017, Ac2orn began actively moving forward on priorities that had been established via conducting a Needs Analysis, embedding ourselves in multi-disciplinary scientific teams and iterative feedback with the pediatric and AYA oncology communities.

Our work demonstrated to us that beyond question the number one issue in pediatric oncology in Canada is out of province and out of country access to early phase clinical trials.

The problem exists because provincial regulations restrict access for children, adolescents, and young adults ("CAYA patients") by denying coverage for standard aspects of medical care that are provided within the context of a clinical trial of an investigational treatment when that patient travels outside their home province.



With a White Paper on this issue in hand, Ac2orn began working on a proposal to present to the Federal Minister of Health in calendar year 2018.

We also engaged a Health Economist in an effort to move this initiative forward. The meeting itself did not happen until calendar year 2018, so we hope to be able to provide additional information on this initiative in the next annual report.

AMERICA  
**September**  
**Childhood Cancer Awareness Month**



**AMAZON TO DONATE \$1 MILLION TO THE AMERICAN CHILDHOOD CANCER ORGANIZATION**

**10 million boxes to GO GOLD® to support ACCO**

In September, 2017 on the occasion of International Childhood Cancer Awareness Month, Amazon joined GO GOLD® to help the American Childhood Cancer Organization (ACCO) raise awareness and elevate childhood cancer as a national health priority. According to the National Cancer Institute, approximately 16,000 children in this United States are diagnosed with cancer each year.

Amazon donated \$1 Million to help ACCO fund initiatives that provide educational, financial and emotional support to children and families in communities across the nation. In addition, the online retailer transformed 10 million shipping boxes gold to raise awareness of the gold ribbon as the international symbol of childhood cancer.





**AMERICA**



“Childhood cancer is the leading cause of death by disease in children in the United States,” said Ruth Hoffman, mother of a childhood cancer survivor and Executive Director at ACCO. “What’s more, two-thirds of children who do survive will develop long term late effects. One-fourth of those children will have a life-threatening side effect, including secondary cancers from toxicity of treatment. Despite these statistics, in the past two decades, only 3 new drugs have been approved by the FDA specifically to treat childhood cancer. This compares to more than 182 drugs approved for adult cancers. To make matters worse, while children are fighting for their lives, these young families also face extreme financial hardship because of the costs related to treatment. Such a devastating problem requires creative solutions and collaborations. We are deeply grateful and inspired by Amazon’s donation and investment in this cause.”

Dave Clark, Senior VP of Worldwide Operations for Amazon said, “You cannot underestimate the emotional and financial toll cancer can wreak on a family. ACCO is dedicated to supporting them on the journey and fighting this terrible disease. Amazon is proud to join them in this fight.”

ACCO is also extending their awareness campaign to states across the country. Currently, 35 state governors have signed a proclamation of support recognizing September as Childhood Cancer Awareness Month. With a goal of pushing that number to fifty, ACCO aims to have 100% participation in the effort.

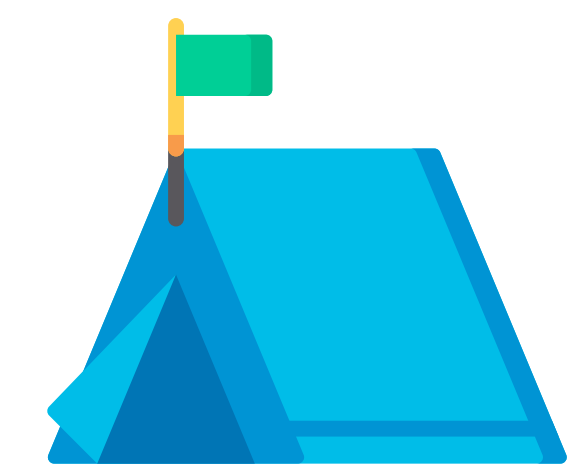
**“Children from all fifty states are affected by childhood cancer. 35 states have declared September official Childhood Cancer Awareness Month -- that leaves 15 to join. We believe it’s critical to raise awareness in every corner of the country so that children can be diagnosed earlier, policymakers can make more informed decisions, and families can be supported by their local communities during such a devastating time,” said Clark.**

The American Childhood Cancer Organization was founded in Washington, D.C. in 1970 by parents of children and adolescents diagnosed with cancer to advocate for their needs and support research so every child survives and leads a long and healthy life. Since its inception, the ACCO has helped support more than half a million families affected by childhood cancer. For more information visit [www.acco.org/amazon](http://www.acco.org/amazon).

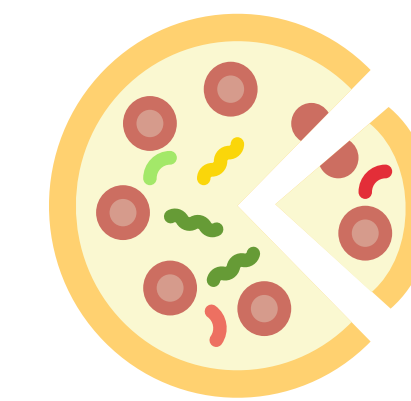
**A. How we touched Lives of children / adolescents with cancer and their families in 2017**



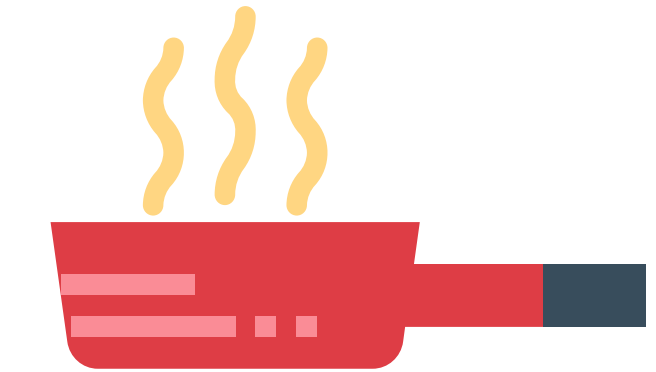
**2,390 participants enjoying year round outreach programs**



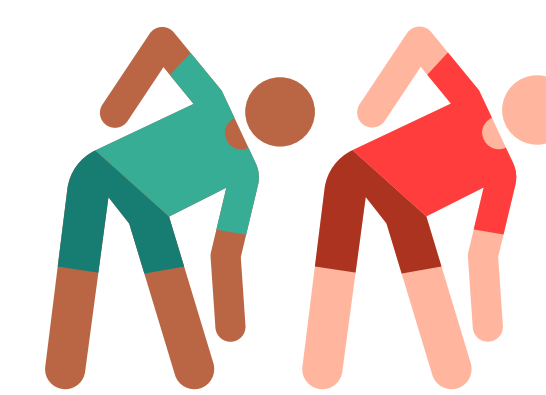
**725 happy campers experiencing the magic of togetherness and discovery in camps**



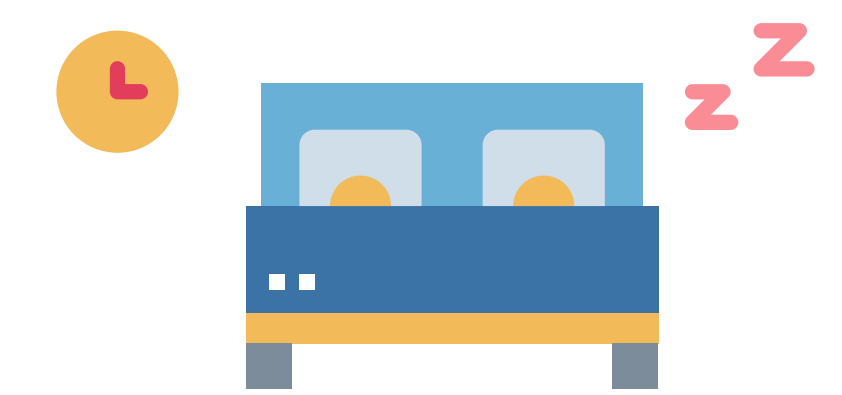
**779 pizzas bringing families together during weekly Pizza Nights at the Hospital**



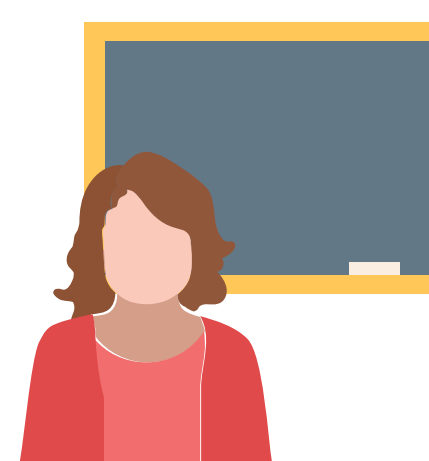
**354 home-cooked meals nourishing families through our Cooking and Caring program**



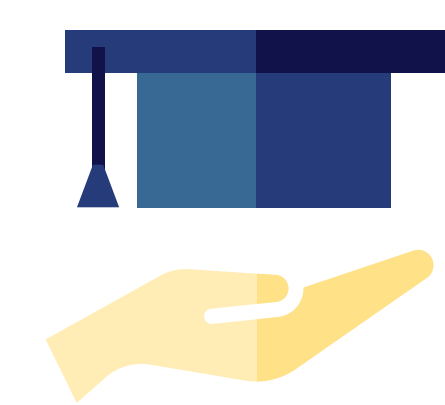
**41 kids rebuilding their strength during weekly exercise programs at PEER**



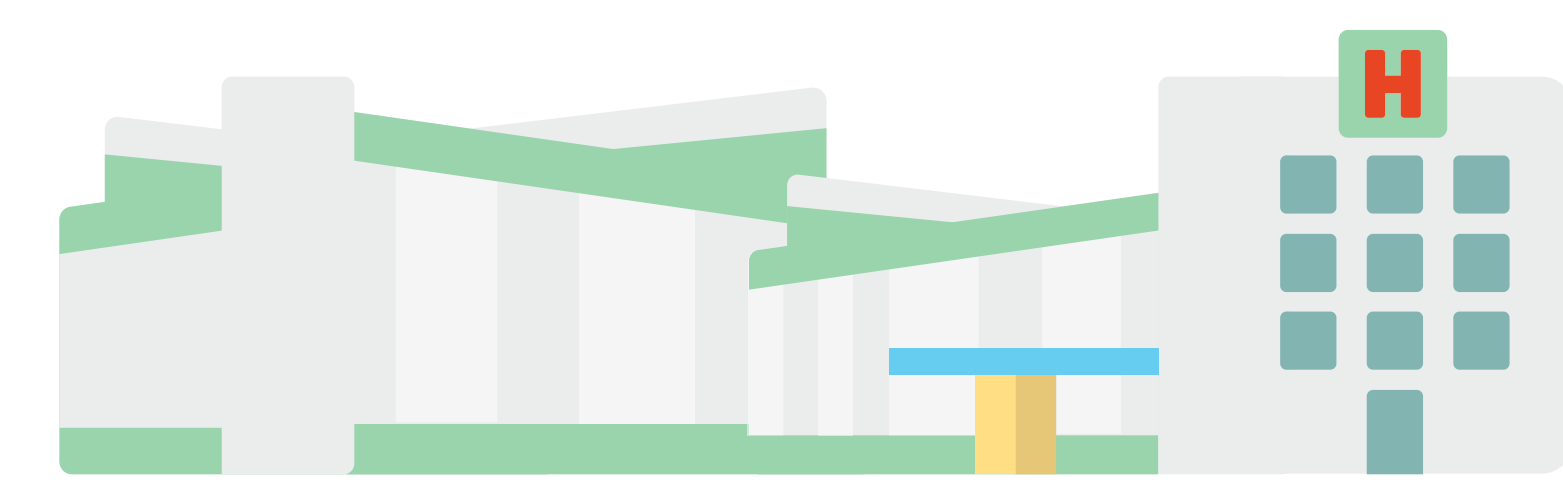
**41 hours respite and renewal for parents in our Parent Program**



**27 kids in need benefitting from 920 hours of tutoring support and planning**



**\$28,500 in scholarships awarded to 10 survivors to follow their dreams**



**1,897 square feet of new research space making new discoveries and new therapies possible for children with cancer**

**B. The Power of Volunteerism**

**Volunteers gave 24,000+ hours to make our programs possible, saving the foundation \$648,000+ or the equivalent of 12 full-time positions**

**For every \$1 invested in fundraising activities our supporters gave back \$3+ to make our programs and services possible**





## 📍 LATIN AMERICA



2017 was a growth and transition year for CCI LATAM. **A major milestone was the formation of** a more representative CCI LATAM Regional Committee with membership from 6 organizations in 4 countries. This is composed of Dr Marcela Zubieta, Chile, Regional Head; Elizabeth Campos, Colombia, Executive Secretary; members Alexandra Matus, the Dominican Republic; Leslie Ducret, Panama, Yolima Mendes, Colombia, and Erik Estanziola, Panama, legal advisor.

The creation of this regional leadership team led to revitalized work **and development of more joint activities in the region.** Other **major milestones** involved a) **Strategic, participatory planning and the** development of the LATAM 5 year Strategic Plan which provided **a clearer horizon of action** for their desired shared future, b) Conduct of the LATAM Annual Regional conference after two years of not being able to come together, c) Establishment of an updated data base on active members of the network and potential areas of joint action/collaboration and d) Creation of a whats app group to strengthen communication and connectivity among CCI members of the region and other local supporters

These **initiatives** marked a new level of collaboration among CCI members in the Region, characterized by more active participation, full engagement in joint work across countries in the Region based on different contexts, needs and interests.

## II. Highlights of the 2017 CCI LATAM Regional Conference

This was held in Sto Domingo, Dominican Republic from August 23-25. The theme was "Building A Stronger Network for fighting Childhood Cancer in LATAM. There were thirty seven (37) participants representing 19 organizations from 10 countries: Argentina, Bolivia, Colombia, Costa Rica, Dominican Republic, Honduras, Panamá, Haiti, Ecuador, Mexico. Alexandra Matos de Purcel, President of Fundación Amigos Contra el Cáncer Infantil of the Dominican Republic (FACCI) welcomed and hosted delegates.



## Four key strategic thrusts were identified during the strategic planning and conference discussions:

**Promote the growth of CCI in LATAM. This involves increasing the number of CCI LATAM members and strengthening connections and involvement of current members.**

Key initiatives to be undertaken are;

- Develop Regional Directory of members and non-members:
- Engage and Invite new members to join CCI LATAM and participate in Cross Country / Regional CCI initiatives. Follow up members whose membership payment are not current. To facilitate this, a representative by country was elected to look for, contact and invite potential new members.
- Mobilize the CCI LATAM network to : a) gather information on local key stakeholders/ local companies and potential supporters / community influentials; b) maintain the communication among members and c) support countries of the region during emergency situations.

**Ensure the representativeness of activities and initiatives undertaken in the region with CCI Regional Members, supporters and local stakeholders.**

Key initiatives to be undertaken are;

- Reached agreements on identification and systemization of the Regional work themes:
- Delineated direct or indirect themes of interest to the CCI LATAM region
  - o Indirect: Global and National Impact actions. Educating different levels, National Programs on Early detection and Healthy lifestyles, etc. Raising awareness of CCJ and promoting Childhood cancer focused research
  - o Direct : Psychosocial Support, Mobilization support, Food, Schooling, Entertainment, Home repair/ Other practical family needs ; hospital / health facility . Infrastructure and equipment; Medical Support in whole cancer care continuum from Diagnosis, Treatment, Follow-up, Nutrition, Supportive and Palliative Care, Rehabilitation
- Identified common program interests were : Survivorship , Adolescent, Youth and Young Adult Cancer, Palliative Care To gather as much information as possible of palliative care of the countries of CCI Latam members.



# HEROES COME IN ALL SIZES.



## Expand scope and coverage to include organizations in the Caribbean

Key Actions to be undertaken include a) Identifying and reaching out to Childhood cancer focused and / or related organizations in the Caribbean and b) Developing a directory of organizations working in LATAM and the Caribbean



## Strengthen real time communication and collaboration among the LATAM CCI members network by a)

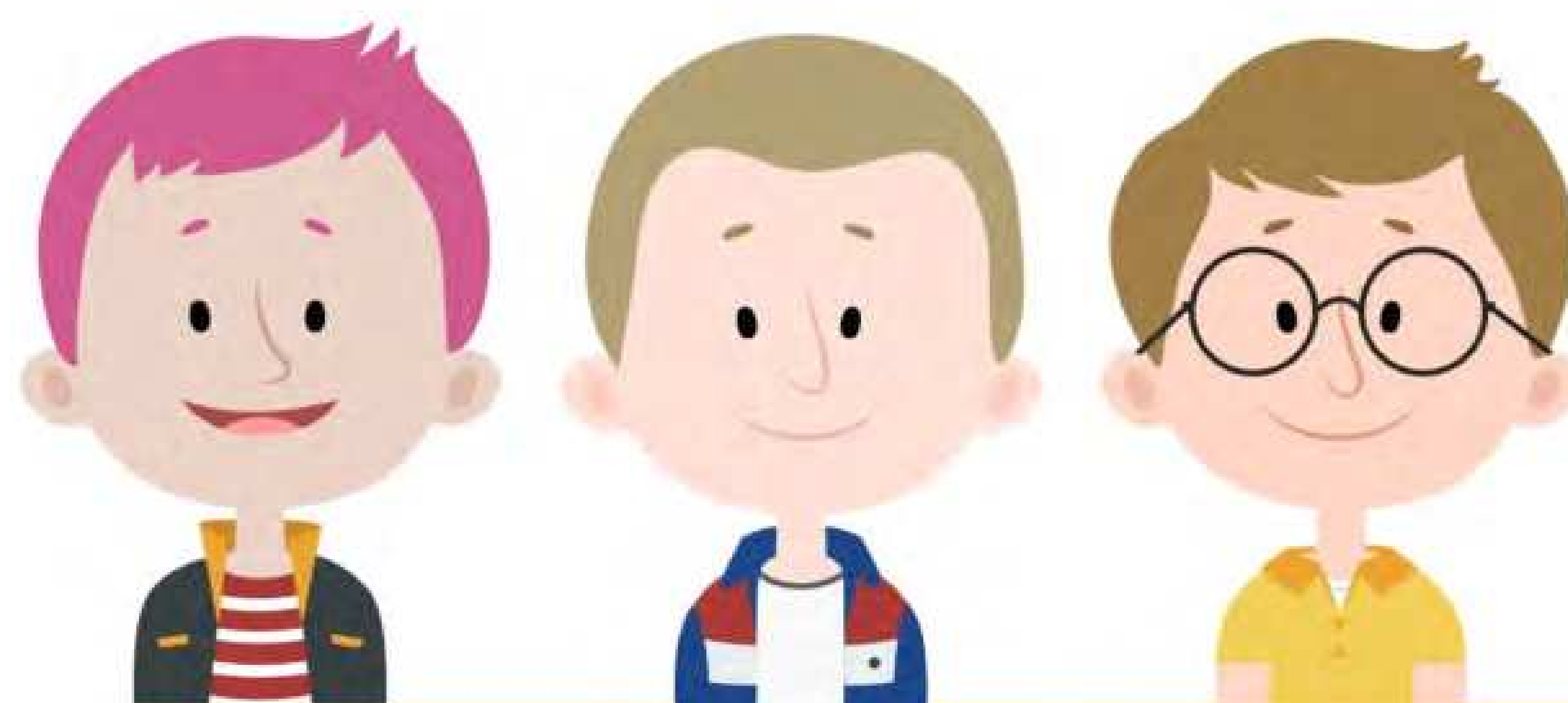
Maintaining and expanding the Whatsapp Group, b) Creating and publishing a CCI LATAM newsletter , c) Creating CCI LATAM webpages containing updated Regional News , LATAM specific learning , information and research materials



## III. Researches and Studies on Childhood Cancer and related organizational strengthening.

- Study on Access to barriers in children and adolescents with cancer in the Columbia Region, Bogota and Costa Caribe. The Columbian Foundation for Leukemia and Lymphoma spearheaded this study in order to determine gaps and blocks to access to care that need to be addressed.
- Completion and scaling up of Childhood Cancer LATAM Mapping of 17 countries which revealed policy and practise strengths and gaps in the areas of Leadership and governance, Service delivery , Financing , Logistics Management and Stakeholder engagement . The study was undertaken by Universidad de Chile research team, under the sponsorship of Fundación Nuestros Hijos (FNH) Chile, Childhood Cancer International (CCI), Union for International Cancer Control (UICC), , Unit for Policy and Economic Research in Childhood Cancer (PERCC) - SickKids, and Pan- American Health Organization (PAHO). Given the wealth of information gathered from the LATAM mapping study, PAHO has now committed to scale up and expand the study to all Caribbean countries . **Results of the study allowed CCI LATIN AMERICA to prioritize 6 countries for regional support /action Bolivia, Ecuador, El Salvador, Honduras, México, Panamá. This also served as basis to determine regional and country priorities and issues to provide better access to care and to medicines, improve survivorship, reduce abandonment, enhance capacities of health professionals, improve health infrastructure in the various countries and complement the medical support in diagnosis, treatments, follow-up, nutrition, palliative care, rehabilitation and patient/-survivor follow up /tracking.**
- Undertaking Institutional Assessment through a self guided checklist. This is part of the process of Capacity Development and Organizational Strengthening for the CCI member organizations in LATAM . This benchmarking activity and assessment will allow organizational development and strengthening in the areas of Administration , Finance and Program Level processes and practices . Completing this assessment is also an organizational commitment to transparency and accountability . It was agreed that in 2018, three organizations (Foundation Giámala-Costa Rica, Marble Guadalajara-Mexico, Foundation La Divina Providencia, Colombia) will go through a first stage of review, and consensus planning.

- Commitment to collect information on:
- Country Laws in palliative care that is covering or affects children with cancer
- Percentage of children that die at home
- Problems in the implementation and management of palliative care





## IV. Distinctive Activities for Raising Childhood Cancer Awareness and Increasing Understanding of Childhood Cancer

In support of International Childhood Cancer Day (February 15th), the Columbia- Fundación Colombiana de Leukemia y linfoma- Sanar spearheaded the Lighting of the Colpatría Tower with the Golden Ribbon being showcased.



The Torre Colpatría is a 50-story skyscraper in the downtown area of Bogotá, Colombia. It's the third tallest building in the country and the fifth-tallest in South America.



Showing of Paco Arango film "What Really Matters" (Lo que de Verdad Importa), titled The Healer in its English version. Paco Arango is a renowned, multi awarded international filmmaker and philanthropist. This film raises awareness about childhood cancer, shows linkage to family, socio-economic realities and mobilizes additional support and resources for childhood cancer foundations of the region located in Costa Rica, Columbia, Panama, Mexico, among others. Paco wrote the final song in the movie, inspired by a 14-year-old girl who thanks Paul Newman for the camps he has supported and maintained for children/adolescents with cancer. This song has become the anthem of the camps run for children/adolescents with cancer.



Inauguration of the Oncology Rehabilitation Center of Fundación Nuestros Hijos- Chile undertaken simultaneously with the celebration of the 2017 International Childhood Cancer Day. 80 per cent of children who survive cancer suffer physical or cognitive impairments either due to the cancer or because of the treatment they underwent. This center bring together in a modern, state of the art, dedicated facility different specializations such as :Differential Education , Physiatriy, Phonoaudiology, Kinesiology, Neuro-psychology, Nutrition, Pediatric Dentistry, Occupational Therapy, Psychology and Social Work



ONCOLOGICAL REHABILITATION CENTER  
1,063 views

<https://www.youtube.com/watch?v=DUV0XjdDar4>

In 2011, Paco wrote and directed his first film 'Maktub' with Warner Bros, in which he wanted to portray what he had learned from the children with cancer, and for which he was nominated three times for a Goya. Fundraising from the film financed one of the most advanced bone-marrow transplant units in Europe: the Maktub Center for Bone Marrow Transplantation at the Niño Jesús Hospital in Madrid. Currently, 171 transplants have been performed. "I'm a filmmaker. When I work I move away from the hospitals, it's the only time I'm not with the children. I will always do charitable movies because all my income will go to help them," he says with passion.

Panamá, Fundación La Divina Providencia, undertook a campaign in the shopping centers and disseminated a campaign to teach the public on the 12 signs used for early diagnosis of childhood cancer.





Ecuador, Jóvenes Contra El Cancer (Youth Against Cancer) : Spearheaded conduct of "Talks for Life", addressed to the youth and focused on promoting healthy lifestyles, inclusiveness and value of dreams/ambitions . It reached more than 60,000 students. Jovenas Contra El Cancer also maintains an International Youth Network of survivors, under the concept of "Love and Cancer; Without Borders. It has also developed youth focused materials for childhood cancer survivors on leadership and coping with life after cancer.



Honduras. The Honduran Foundation for Children with Cancer celebrated ICCD2017 by holding a day long family and community event known as Festival "Heroes for Life" . This is to honour the young heroes who fight daily against childhood cancer and the angels that give their blessings from heaven. They walked up the Cerro Juana Lainez, did a Zumba dance and launched balloons to celebrate and pay tribute to the héroes and angels. [Read More](#)



**V. High impact programs carried out by LATAM members in palliative care and pain mangement, nutri-tion, education**

**Palliative Care and Pain Management**

Chile, Fundación Nuestros Hijos. The foundation spearheaded the publication of a Guideline for Parents and Carers of Children and Adolescents with cancer at home; this is part of an international Project of palliative care and pain relief for children with cancer in four South American countries. This is a follow up activity to the previous capacity building /training and coaching of health service providers from health facilities in Bolivia, Colombia, Peru and Paraguay.

The guideline is being used in the pediatric oncology units of participating institutions in these four countries. The main topics are pain/pain management, respiratory problems, nutrition, rest and sleep, skin state, communication, beliefs and values, among others. This program is financed by Fondo Chile, with the Agencia Chilena de Cooperación Internacional para el Desarrollo (AGCID) and Programa de las Naciones Unidas para el Desarrollo (PNUD). Chile, FNH. Palliative Care and Pain Management capacity development program undertaken for health service providers in selected childhood cancer facilities in Peru, Bolivia, Paraguay and Colombia.



Colombia, Sanar: They provide assistance in the decision making process of the parents or legal guardians of the child or adolescent for whom palliative therapy is being considered. This ensures that the decision they make is well informed, taking into consideration psychological, biological and social factors. During palliative care, the foundation also ensures continuation of psychological support for the child and his/her family.

México, CANICA: Supports palliative care at home. When there is no longer a cure protocol, CANICA offers the child and his family the needed resources so that they can return home; they put in their service a palliative care pediatrician, psychologist, nurse, social worker and volunteers as well as provide them with the required medical equipment and pain medications. They have provided this care for 86 children and their families

Workshops for parents, in collaboration with SENTEC (Oncolofeliz)





**Nutrition**

Colombia, Sanar: Their nutrition program seeks to educate and inform parents and caregivers on the importance of proper nutrition, the creative preparation of meals and use of food. They also provide specialized nutritional support to families that need it.

Chile, Fundacion Nuestro Hijos (FNH). They provide support to families, carers and teachers on proper nutrition. In collaboration with the government of Chile and other supporters, they provide free nutritious food in their educational centers.



México, CANICA: Sponsors workshops, talks and conferences that serves as a guide to good nutrition, improves the nutritional status of children with cancer and strengthens them to support their treatment in an optimal way.

**Education**

Chile, FNH: Consolidation of the school reintegration program in schools of origin by the area of education.



Colombia, Funleucemia: Provide spaces of information, education and emotional support to parents and caregivers of children with cancer, in subjects related to diagnosis, self-care and health system.

Colombia, Sanar. Undertakes "Reading for Healing", a psychological support program that seeks to promote reading in unconventional spaces such as the hospital. It generates therapeutic processes from reading and the arts.

México, CANICA: Provide school education to children and youth with cancer, promoting their development and regularizing their school year. They have graduated 551 students from their school.



**CANICA MAKE DREAMS COME TRUE**  
Mexican Foundation Canica (marble), hosted kids from South and Central America to brought them to see Disneyland and other iconic places in California.

**VI. High Impact in country advocacy initiatives that CCI members in LATAM did include the following.**

- Argentina. Advocacy for construction of an "ambulatory surgery center" in Mateo Esquivó.
- Colombia. Advocacy for passage of a new law through the Colombian initiative International Observatory for Childhood Cancer (OICI), Colombia-SANAR-FUNLEUCEMIA.
- Ecuador. Advocating for access to childhood cancer medicines and treatment access; advocating to the Ecuador authorities to consider childhood cancer as a catastrophic disease (Fundación Jóvenes contra el cancer).
- Haiti. Advocacy with congress members and health insurance companies for a new health access law in Haiti (FHACI).

**Even if just for today, please think about childhood cancer.**





# STORIES OF HOPE

## “Tomas’ White Awakening”

### Fundacion Nuestros Hijos’s Rehabilitation Center

### Chile



"Mom, I have a headache", that was the sentence that started the family calvary for which no one is prepared. Paracetamol did not help and the pain was compounded by vomiting that led Marcela to consult at the Hospital, what s happening to her son who, until then, was in perfect health.

At the age of 12, Tomás played soccer, danced, laughed with his twin brother, hugged his mother, went to school, talked with his classmates. It was the opposite of what Marcela embraced the day his son woke up from the induced coma, after the different interventions they did in the Hospital to treat their tumor lodged in the brain.

"Tomy did not do anything, his diagnosis was horrible, they told me that he would always be like this, without moving, without expression: that is what God wants" Marcela tells with a trembling voice.



#### REHABILITATION BEGINS

Vera Celedón, technical director of the Oncology Rehabilitation Center of Fundación Nuestros Hijos tells us: "At the time of his admission in October 2016, the interventions to Tomas's brain tumor had impacted in a state of minimal response, without reactions, or movements, in addition,his arms and legs were completely rigid

Our rehabilitation professionals moved to the oncology hospitalization section of the Sótero del Rio Hospital to treat him. "As the sessions passed, it seemed that Tomás listened and understood instructions."

Once stabilized, Tomás was discharged and sent home. Fundación Nuestros Hijos (FNH) provided a clinical cot, an special mattress to avoid skin sores and a neurological wheelchair so that both, Tomás and his family, could have a better quality of life. In addition, FNH financed the daily transfers to the Oncology Rehabilitation Center, where he received intensive therapies in kinesiology, occupational therapy, speech therapy, neuropsychology and psychology.

He began to respond to certain stimulus performed by the therapists in the multisensory stimulation room. The flavors, smells and places makes Tomás reacts. The team were able to establish a communication method through gestures of his face.





## TOMAS WHITE AWAKENING



According to Marcela, July 15, 2017 would be a special day for the city and especially for their family: "That day, Tomás' older brother came crying and running to embrace me:

- Son, why are you crying?

-Mom! Tomy spoke to me!

Since my son entered to the Oncology Rehabilitation Center of Fundación Nuestros Hijos, Tomy began to move more, opened his mouth, then spoke, improved his pronunciation, used his hands, moved his feet. He began to feed by mouth, overcoming a paralysis of his stomach. The change has been from heaven to earth. "



The Tomás therapy and his achievements have continued to grow over time, allowing that child who was going to be in vegetative state, now could move! In FNH we chance his wheelchair without support for his neck, He stands up with a walker support, crutches and finally walk again.



Tomás, now with 14 years old has returned to kick a soccer ball, moves his body to the rhythm of music, his face expresses smiles with anyone who crosses his path, has new colleagues to talk at the FNH Hospital School; Marcela, her mother, has returned to wrap her arms around that child that woke that snowy day of Santiago.



**Survival in Chile reaches 75%. Rates closed to developed countries. This anomaly, is in part thanks to the public-private collaboration model, through NGOs such as Fundación Nuestros Hijos.**

**These good results generates new challenges to improve the quality of life of children during all stages of the disease. 80% of children may have some physical or cognitive sequelae by the cancer itself or the used treatments. Without integral rehabilitation therapies, 35% will have problems that will affect their quality of life and therefore their entire family circle.**

**In September 2014, after visiting different Rehabilitation Centers in the United States and Canada, Fundación Nuestros Hijos starts a Child Oncology Rehabilitation Center to help all the children in Chile.**

**Through ten clinical specialties, Fundación Nuestros Hijos delivers the specific rehabilitation therapy that the child needs, in any of the stages of the disease, including Palliative Care; and for as long as it is required. FNH have the specialists and the latest generation equipment through a biosafety environment for immunocompromised children that make this center "unique" in Latin America.**



# 2017 ANNUAL CCI REPORT HIGHLIGHTS

## CCI GLOBAL KEY ROLES



### 1. Knowledge Leader

**Awareness Building**  
**Promoting good practice models, best practices and innovations**  
**Endorsing and disseminating landmark researches and studies**

### 2. Catalyst

### 3. Advocate

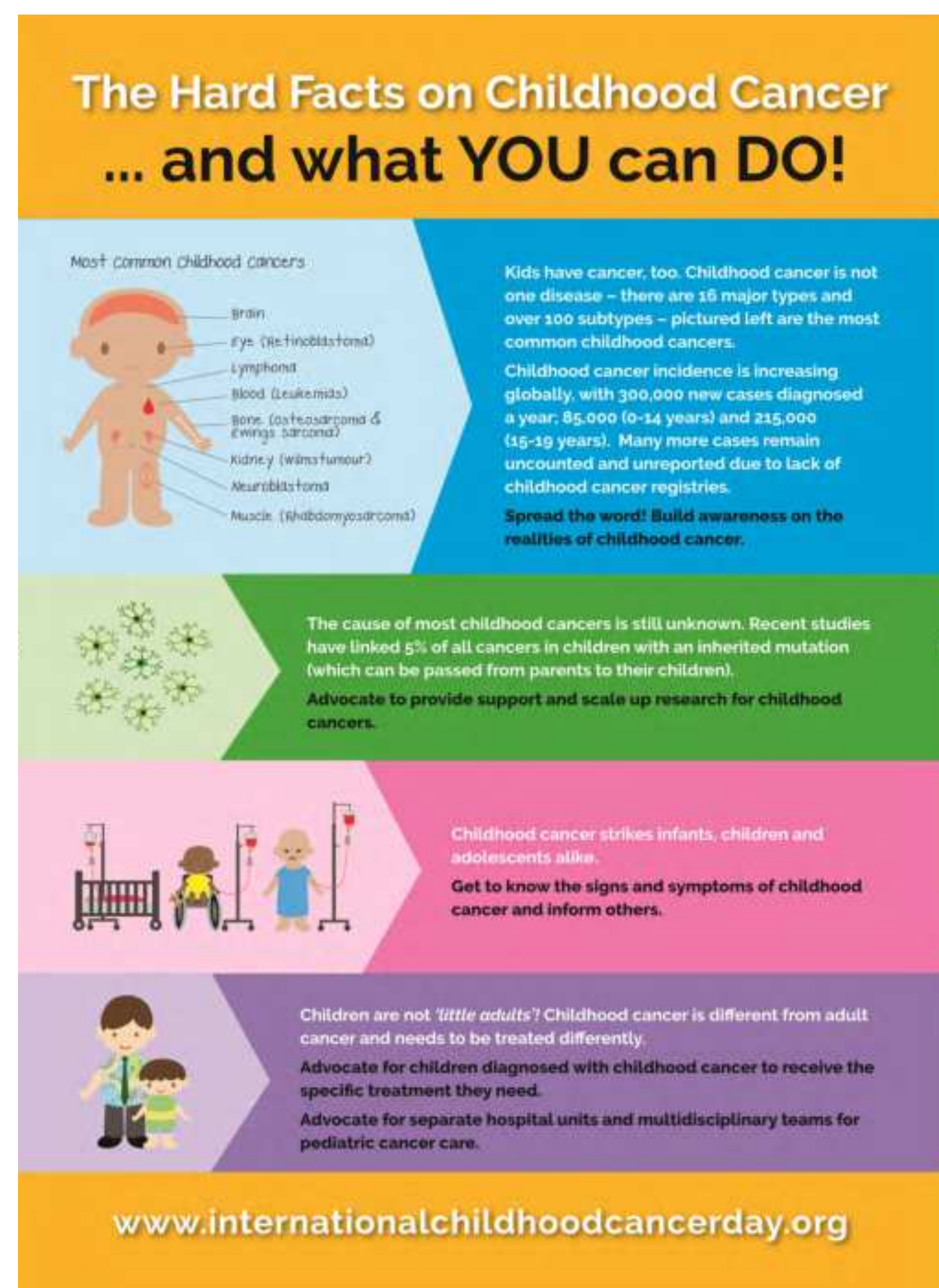
**driving change for childhood cancer care and cure**

### 4. Mobilizer

**Gain widespread support for childhood cancer initiatives through Partnership Building, Networking and Alliance formation**

## FIRST GLOBAL CHILDHOOD CANCER INFOGRAPHIC

**Build awareness**  
**Deepen understanding**  
**Correct misconceptions**  
**Galvanize action**





## 2017 Theme : Together for kids with cancer

### ICCD Campaign GAINS Wider SUPPORT from National Governments and INGOS

- UNDP and UNICEF Country engagements
- Ronald McDonald Charities (social media)
- Camp Quality (social media)
- Global Goals – Australia Campaign for SDG
- Canadian and EU government social media sites
- ECCO
- Ontario Parents Advocating for Children with Cancer







# TOGETHER... STRONGER









## A Better Understanding of Childhood Cancer Survivors

### MYTHS AND FACTS INFOGRAPHIC

**MYTHS vs FACTS: Childhood Cancer Survivors**

MYTH	FACT
 <p>X Survivors are disease carriers and pose health risks to others.</p>	 <p>✓ Childhood cancer isn't contagious: it's not transmitted by a virus, nor is it infectious. It's safe to play, socialize and interact with childhood cancer survivors.</p>
 <p>X All survivors are genetically inferior and have fertility problems. They can never have children</p>	 <p>✓ Some survivors may have fertility and reproductive issues, but this isn't true for most survivors, as the type of cancer and its treatment determines if they'll have any fertility challenges.</p>
 <p>X Survivors have short lives.</p>	 <p>✓ While two out of three childhood cancer survivors are at increased risks for late effects and secondary cancers, this isn't linked to life expectancy. The nature and severity of subsequent late effects also influences life expectancy. Reductions in life expectancy depend on:</p> <ul style="list-style-type: none"> <li>• How timely the cancer diagnosis was,</li> <li>• What the initial treatment was, and</li> <li>• The appropriateness of the treatment received.</li> </ul>

[www.childhoodcancerinternational.org](http://www.childhoodcancerinternational.org)

MYTH	FACT
 <p>X Childhood cancer survivors are cured. Survivors no longer need continuing, follow up care.</p>	 <p>✓ Continuing follow up care remains important for survivors. They are at higher risk for secondary cancers, or chronic health conditions related to their initial cancer treatment. Vigilance and regular monitoring are critical for early identification and treatment of any health challenge, or impairment.</p>
 <p>X Childhood cancer survivors will have a miserable, sad and dismal future. They can't ever have a normal life.</p>	 <p>✓ There's life and a future after cancer. There's a 'new normal' after surviving childhood cancer. Most survivors are able to return to school and regular activities after treatment. Survivors can effectively reintegrate with family, friends and their communities. Their adjustment to life after cancer becomes much easier, more fulfilling and happier, with a circle of supportive care from family members, teachers, carers, peers, friends, neighbors and the community at large.</p>
 <p>X Survivors do poorly in school and employment.</p>	 <p>✓ There are survivors who may have cognitive and learning disabilities, but this is not true for everyone. Most survivors are high performing achievers who do very well in their education and career.</p>

[www.childhoodcancerinternational.org](http://www.childhoodcancerinternational.org)



## Convened CCI regional Conferences and meetings

- CCI Asia : Thailand . 100 + /17 countries
- CCI Africa: Marrakech
- CCI Europe : Rome

- CCI Latin America. Dominican Republic. 37 participants, 10 countries
- Oceania.



## Board Country Support Visit: Indonesia

- CCI Board Members Engage with Indonesia Ministry of Health and
- had a Multistakeholders Dialogue with Indonesia Childhood Cancer Organizations and Societies . MOH and WHO



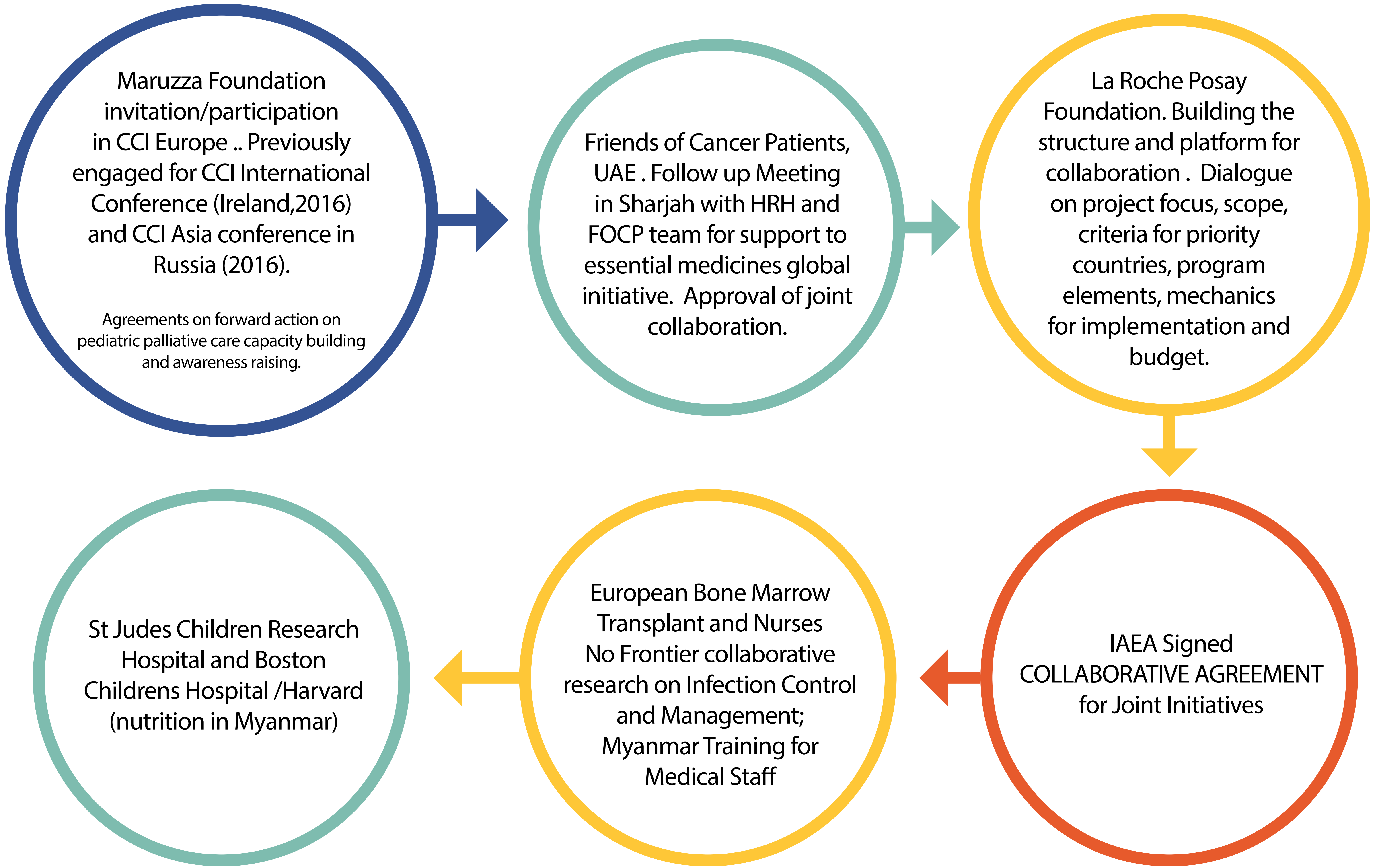
## Pursued Official Relations Status with WHO

- Preparation and submission of 3 year work plan for priority countries: Myanmar, Ghana, Ethiopia
- Preparation and submission of Non State Actor Report (what we/CCI did the past 3 years )
- Continuing on ground work in priority countries (Myanmar, Ethiopia, Ghana)
- Participation in WHO Geneva Global Childhood Cancer meetings





# STRENGTHENED AND EXPANDED ALLIANCES



# CCI ASIA GROWTH FUND SUPPORTED INITIATIVES

