



# Childhood Cancer International

CREATING BREAKTHROUGHS FOR CHILDREN WITH  
CANCER, THE SURVIVORS AND THEIR FAMILIES



Every 3 minutes a child is diagnosed with cancer and 80% of these children and adolescents live in low and middle-income countries where access to quality care is limited and chances of a cure are low!

Childhood Cancer is the Leading Non-Communicable Disease (NCD)-related Cause of Death of Children Regardless of Where They Live in the World!



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## Incidence

Is Increasing.

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## # Survivors

Is Increasing.

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## # Deaths

Is Increasing.

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# Message from our Chair



**Twenty six years ago, our founding members made a promise to all children with cancer of the world. They made the commitment that children with cancer everywhere, will get the best possible treatment and care. Their vision, passion and determination is what brought us to where we are today.**

Last year, in Toronto, Canada, we rededicated ourselves as a board, to honour that commitment and make 2015 the year when we CREATE BREAKTHROUGHS for children/adolescents with cancer, the survivors and their families.

After years of being known as ICCCP (International Confederation of Childhood Cancer Parent Organizations), we renamed ourselves Childhood Cancer International (CCI) to capture the reality that we are no longer just parents organizations but include survivors associations, childhood cancer support institutions and national federations. To reinforce that message and our role as catalysts in ensuring better access to care for children/adolescents with cancer, we entwined the gold ribbon in our logo (the globe). The Gold Ribbon symbolizes childhood cancer and the bravery and courage of children and adolescents with cancer. Its presence in the CCI logo conveys our determination to work together to achieve lasting and significant changes in childhood cancer care and ensure that the rights and well being of all children/adolescents with cancer everywhere will be protected.

This year, we strengthened the reach and scope of our global advocacy by a high impact side event (in collaboration with SIOP), at the World Health Assembly in Geneva. As a result, the

World Health Organization has now convened a Task Force on Childhood Cancer to map out a platform of action.

We intensified our awareness campaign by creating the multi-stakeholder global campaign ACT NOW. We expanded the CCI-SIOP-UICC alliance and engaged other robust international coalitions and organizations like NCD Child, the International Pediatrics Association (IPA), The Max Foundation (TMF), St Baldricks Foundation and International Children's Palliative Care Network (ICPCN). This significantly expanded the reach and increased the impact of the International Childhood Cancer Day celebrations.

We launched the International Childhood Cancer Survivors Week to bring focus to our message that many childhood

landmarks, monuments and buildings. This year, we will continue to transform ourselves into a more dynamic, agile, and robust global network committed to three strategic goals: Collaborate, Consolidate and Innovate. We will continue to work with diverse stakeholders who will enable us to integrate childhood cancer in other child health and development platforms. We will join our voices and consolidate our forces so that we can do more for kids with cancer, the survivors and their families. We will innovate—initiating new and better ways to serve children and adolescents with cancer, childhood cancer survivors and their families.

Thank you everyone for your unwavering commitment and steadfast dedication towards saving lives and ending avoidable deaths from cancer.

***Working together, we will create  
SUSTAINABLE CHANGE with  
ENDURING IMPACT on the lives and  
future of children with cancer, the  
survivors and their families.***

cancers are now curable and there is life beyond cancer. In order to LIGHT UP HOPE during the International Childhood Cancer Awareness Month (September), we collaborated with organizations that LIGHT UP GOLD iconic and natural

*Carmen*

# Governance and Membership

## Board of Trustees

The CCI Board of Trustees is composed of representatives from member organizations who have a full member status. Board members are elected for three years and can be reelected for an additional two terms or a total of 9 years. The Chair and Vice Chair have a three year term of office.

In the 2014 General Assembly in Toronto, Carmen Vallejo Auste from the Philippines (Cancer Warriors Foundation) was elected as Board Chair while Ruth Isabella Hoffman from the USA (American Childhood Cancer Organization) became the Vice Chair.

Luisa Basset (Spain) and Mary McGowan (Australia) were elected as new members. Kenneth Dolman (Immediate Past Chair) was re-elected for his last term as board member. Edith Grynszpancholc (Argentina) and Anita Kienesberger (Austria) stepped down from the Board of Trustees after having completed their terms of office. Edith and Anita continue with their roles as head of CCI–LATAM and CCI–Europe Regional Committee, respectively. In the current board, Luisa Basset (Spain) and Poonam Bagai (India) assumed the roles of Board Secretary and CCI Corporate Treasurer respectively.

## Membership

CCI represents 177 parents, survivors and childhood cancer support organizations in 90 countries, across 6 continents. A recent survey revealed that CCI has 20 member organizations that are national networks, federations or umbrella organizations, having operational presence in their whole country and representing an additional membership of no less than 127 organizations. This means that CCI represents a total of 304 organizations all over the world.

CCI global network includes member organizations from both high resource and resource challenged countries. Europe, 61 members in 32 countries and the Americas (North America and Latin America), 42 members from 19 countries, account for more than half of all members. Asia, Africa and Oceania account for the remaining with Asia and Oceania having 52 members from 23 countries and Africa, 22 members from 16 countries.

The General Assembly accepted 8 new members– 5 full and 3 associate: 4 were from Africa (Cameroon, Malawi, Nigeria, Zimbabwe), 3 from Europe (Georgia, Ireland, Switzerland) and 1 from Asia (India). The Australian organization Children’s Cancer Centre Parent Advisory Committee (PAG) applied and was approved to become a full member.

## Head Office

For the past 14 years, VOKK (CCI member in the Netherlands and a founding member of CCI) has hosted the CCI Head Office. Patty Brouwer fulfills the role of International Services Manager while Marianne Naafs-Wilstra (VOKK-CEO and past Chair of CCI) is CCI Board Senior Advisor.

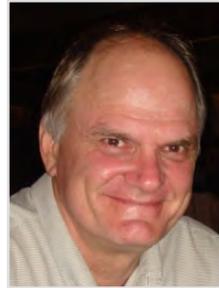
***Childhood Cancer  
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## Board of Trustees 2015



### Carmen Auste Chair

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, Millenium Challenge).



### Kenneth Dolman Immediate Past Chair

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 where none existed before.



### Ruth I Hoffman Vice Chair

Ruth is the mother of eight children, including 35 year old Naomi, a 28 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.



### Benson Pau Past Chair

Benson, father of Kwong Wun who, in 1998 died of leukemia at age 10, transformed his grief into positive energy. He and his wife set up Pau Kwong Wun Charity Foundation to empower childhood cancer patients and their families to improve their quality of life.



### 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.



### 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.



### 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 Kidscan, 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 (Choroid Plexus Carcinoma). The tragic experience made her refocus her professional and social life to serve underprivileged children with cancer living in Chile.

# Regional Footprints

## Working Together to Create Better Access to Care for Children and Adolescents with Cancer

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### *Together We are Stronger*

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#### Asia

**In China**, through the leadership of Benson Pau, the 4th National Childhood Cancer Support Groups Conference was held last August. There were one hundred participants from 14 provinces and cities. This conference also witnessed the creation and inauguration of the Gold-Ribbon Charity Alliance of China in which 12 regional parent support groups joined together. Mr. Benson Pau, CCI Asia Regional Committee Head, was elected the first Chairman.

**In Vietnam**, Asia Children's Cancer League (Japan) collaborated with Hue Central Hospital and the Union for International Cancer Control (UICC) in conducting a Roundtable Discussion for the formation of a Children's Cancer Consortium of Vietnam. This initially involved doctors from hospitals in Vietnam where childhood cancer care and treatment are being provided. The plan is to formalize the Consortium and develop a pediatric oncology strategy plan for Vietnam.

#### North America

**In Canada**, Kids Cancer Care Foundation (Alberta) initiated the formation of a national alliance of children's cancer groups from across Canada called the Big Book of Care for Childhood Cancer Awareness Month (<http://bigbookofcare.org>). To date, 16 groups have joined this national alliance. Sharing resources, ideas and efforts, the purpose of the alliance is to unite as many groups and messages under a single, identifiable brand so their messages may be heard as one powerful message in households across Canada. The goals of the campaign are straightforward: 1/ Increase awareness about childhood cancer; 2/ Educate the public about the disease and the many organizations helping Canadian children with cancer; 3/ Inspire the public to get involved and donate; and 4/ Motivate children's cancer groups to participate.

With the Big Book of Care website as campaign hub, the campaign is designed to inspire and unite people through shared stories. There is power in stories and each campaign

platform (i.e., sponsored PSAs, news stories, website stories, social media posts, fundraising and awareness events) will focus on sharing children's stories both from the child's perspective and that of their family, their doctor, teacher, etc. This national initiative also engaged the private sector and had the support of William Joseph Communications, Shaw Communications, Global TV, Pattison Outdoor Advertising, Corus Radio and Sears Canada.

#### Europe

**In Switzerland**, the Childhood Cancer Switzerland, a coalition of childhood cancer focused organizations was founded at the beginning of 2015 and launched in Berne on 15 February 2015 (International Childhood Cancer Day.) The new organization brings together parents, doctors, survivors and researchers who are committed to increasing public awareness, engaging in advocacy, supporting research and providing assistance to families of children with cancer and survivors. CCI Board Chair Carmen Auste, CCI Founding member, Dr. Gerlind Bode and SIOP-E President Prof. Gilles Vassal were in Berne Switzerland, with more than 150 parents, survivors, volunteers and key stakeholders to celebrate ICCD and launch the new organization. This coalition emerged from the intensified collaboration between Swiss childhood cancer organizations that had formed an alliance beginning 2009.

#### Oceania

Members and friends of CCI Oceania Regional Committee joined the inaugural CureFest Australia on Sunday 27 September. This is a one day event that aims to raise national awareness about childhood cancer as well as educate and inspire the community to act on the issues of childhood cancer.

CureFest Australia is based on an annual event in the United States, which aims to make childhood cancer research a national priority by bringing together the childhood cancer community, the public and government. Curefest was brought to Australia by Amanda Griffin who was inspired by her daughter Erin who died from Diffuse Intrinsic Pontine Glioma (DIPG). Erin asked her mum to continue raising awareness on the issues children with cancer endure. Erin believed the only way to find the cure for cancer was to work together, sharing a unified voice so children with cancer would be heard. Amanda Griffin describes the essence of

the event as, "CureFest Australia tells children affected by cancer and their families that their lives matter, and will no longer walk alone as the Australian community will walk with them. It is our opportunity to say children with cancer matter and together we will beat this disease."

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## *We Care, We Share*

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### **Asia**

Children's Cancer Association of Japan (CCAJ) donated JPY 300,000 (EUR 1,055) to support 25 families of children with cancer in Nepal who lost their homes due to the successive intense earthquakes. These funds were raised by CCAJ during their ICCD initiatives. Hearing of the devastation that rocked Nepal, they wrote CCI about their desire to share these funds with families of children with cancer who were rendered homeless or were dislocated by the earthquake. The CCI members who served as the executing local partners for distribution of these funds were the Children Cancer Foundation (CCFN) under the leadership of Dr. Krishna Sagar and Rudra Kadariya of Children Cancer Nepal (CCN). This innovative humanitarian aid demonstrates the true spirit of solidarity and caring within CCI.

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## *Supporting Capacity Development*

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### **Asia**

CCI-SIOP Asia Twinning projects in Indonesia and China will be ready to start by last quarter of 2015. The Steering Committee of this First CCI-SIOP Asia Twinning project, consists of Dr Akira Nakagawara (current SIOP Asia President), Dr Chi Kong Li (in-coming SIOP ASIA President), Kazuyo Watanabe (Asia Regional Committee member), Benson Pau (Asia Regional Committee Head

and former CCI Chair) and Carmen Auste (CCI Chair). The project will focus on targeted hospitals and challenged areas in China and Indonesia (two of the most populated countries in the region). Benson Pau is Program Manager and will provide leadership to the China side of the program. Ira Soelistyo of Indonesia Care for Cancer Kids Foundation (YKAKI) will steer the Indonesia project which is focused on increasing public awareness on childhood cancer early warning signs and providing trainings for primary health practitioners especially for those in rural and remote areas.

The Hematology & Oncology Center of Beijing Children's Hospital and Prince of Wales Hospital of Hong Kong is working together, preparing the learning program and getting ready to train pediatric oncology doctors, nurses, caregivers as well as parents on pain management. This is envisioned to lead to the improvement of pain care assessment and management in the Beijing Children's Hospital.

Another planned educational and learning alliance is with the European Society for Blood and Marrow Transplant that will train nurses from 9 hospitals in Guangzhou province in collaboration with CCI member organization Gold Ribbon-Guangzhou.

**In Vietnam**, Asian Children's Care League (Japan) has supported Hue Central Hospital, in carrying out local outreach programs to provincial hospitals in the central region of Vietnam. This is part of the self-sustainable initiatives for early detection-referral-diagnosis-treatment and local networking in the area. To raise awareness and funds to support this initiative and children/adolescents with cancer in the central zone of Vietnam, the Hue Central Hospital Parents Group, in collaboration with multiple stakeholders held their first Charity Music Concert. The program was broadcasted live on national TV.

**In Iran**, Mahak (CCI member from Iran and CCI Regional Committee

Member) has completed a benchmarking visit with Kurdistan Save the Children (KSC) & Hewa Hospital and has signed a partnership agreement to contribute to the improvement of the quality of therapeutic and general medical services in support of children suffering from cancer in both organizations. They are also in the process of defining a model for collaboration with the Afghanistan Children Protect Organization (ACPO) and with NGOs in Azerbaijan interested in doing work on childhood cancer.

### **Europe**

In a number of EU funded projects, CCI is a key partner ensuring the involvement of parents and patient representatives. CCI is the only official representative of parents and survivors support organizations in Europe. The six ongoing EU funded projects where CCI is involved are ENCCA, ExPO-r-Net, IntReALL, GAPP, PanCareSurFup and PanCareLIFE

CCI and SIOP-E continues its active and successful collaboration on advocacy for European oncology policy initiatives. They also are actively and jointly engaged in multidisciplinary and multi-stakeholder programs such as PanCare Childhood and Adolescent Cancer Survivor Care and Follow-Up Studies (PanCareSurFup) and ExPO-r-Net (European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment).

PanCare SurFup aims to provide every European childhood cancer survivor with better access to care after treatment and better long-term health. It is a consortium of 16 European institutions in 11 countries, funded by the 7th Framework Programme of the EC, to carry out research studies into three serious late effects of treatment for cancer (i.e., effects of radiation therapy, cardiac disease, subsequent cancers and secondary malignancies), establish guidelines for follow-up as well as models for care and transition, and meet training needs of health professionals. As a collaborative

partner, CCI leads in the area of public awareness and dissemination as well as in the design of guidelines and all informative materials for patients and survivors of childhood cancer.

The goal of ExPO-r-Net is to reduce the current inequalities in survival, by improving the quality of healthcare across Europe. It aims to achieve high-quality, accessible and cost-effective healthcare for all childhood cancer patients in Europe. The project will focus on European countries with lower healthcare capabilities. The European Standards of Care for Children with Cancer serves as the benchmark. CCI is a partner in this project through its member organisation from Austria, Österreichische Kinder-Krebs-Hilfe, headed by Anita Kienesberger (current head of CCI Europe Regional Committee).

IntReALL (International study for treatment of childhood Relapsed ALL). The goal of IntReALL is to develop an optimized internationally recognized standard therapy for children with relapsed ALL so that more young patients can be permanently cured. CCI heads an ethical board (consisting of parents/patients and other non-medical professionals) that assesses the risk/benefit considerations of the trials and reviews the information and consent forms given to patients and their parents. The ethical board is also involved in the design and conduct of the trials and offers counseling to the physicians and stakeholders involved.

### Africa

CCI members in Africa support the strengthening of health infrastructure and systems. **In Tanzania and in Zimbabwe**, Tumaini la Maisha Tanzania (TLM) and Children's Cancer Relief assist with the procurement, both locally and internationally of essential drugs needed. L'Association L'Avenir, CCI member from Morocco go even further and provide medical equipment, drugs and prostheses. In other instances, member organizations fund the establishment and staffing of specialist pathology laboratories for diagnosis and surveillance. Others like CHOC SA in South Africa assist with costs to make available staff needed to manage cancer registries and to run follow-up initiatives. This type of program is expanding to more countries where childhood cancer registries do not exist. AMAL Association des maladies atteints de leucémies (AMAL) in Morocco contributes to improved infection control by providing liquid soap and dispensers in the wards.

**In Zambia and South Africa**, Kayula Childhood Cancer Foundation (KCCF) and CHOC SA have year round continuing programmes to train volunteers to assist in the wards. In Tanzania Tumaini la Maisha Tanzania (TLM) funds and helps the local University run an MSc in Pediatric Hematology - Oncology to train local pediatricians to be specialists.

Programmes also exist to improve completion of treatment and reduce abandonment (i.e., discontinuance of treatment for more than a month). These involve improving the parents or caregivers understanding of the disease and disease process. This is facilitated through "ward mothers" who assist with translations, set up parent-to-parent meetings and coordinate housing in parent homes. Skilling and income generating programmes have also been organized for parents. This forms an important part of ward and parent home life in Africa. One example of this is the program of the Namibia Childhood Cancer Parents Support Organisation (NaCCapso). In most cases, the products produced are sold locally and internationally to generate income not only for the parents themselves, but also for the CCI member organizations support.

### Latin America

There are ongoing cross border collaboration among CCI members in Dominican Republic and Haiti; Argentina and Bolivia (Sta Cruz de la Sierra). The Fundacion Nuestros Hijos is providing technical capacity building and support on pediatric palliative care and pain management to La Paz (Bolivia). Due to a grant from the Fund against Hunger and Poverty, this collaboration will continue and will be expanded to include professionals from oncology units located in Bolivia, Peru, Paraguay and Colombia.

CCI together with the American Childhood Cancer Organization, The New Zealand based World Child Cancer Charitable Trust, the Fundacion Nuestros Hijos and the Fundación Natalí Dafne Flexer, jointly supported the convening by UICC of the McMaster Health Forum in Geneva. The Stakeholder Dialogue focused on Advancing the Development of National Childhood Cancer Care Strategies in Latin America. It brought together 24 participants from across Latin America, Canada and the USA, consisting of policy makers, health professionals and researchers. Edith Grynszpanholc, President of Fundación Natalí Dafne Flexer and head of CCI Latin America Regional Committee represented CCI in this workshop. Four priority initiatives emerged: Scaling up Advocacy, Generating Data and Evidence, Fostering Stakeholder Engagement and Building a Pan Regional Task Force.

The Union of South American Nations (USAN) was organized as a result of the International Symposium on Cancer Policies in South America which was convened by the Chilean Ministry of Health, in association with Pan American Health Organization and the Network of National Cancer Institutions of Latin America (RINC). It brought together researchers, policy makers, implementers and civil society organizations from South America to discuss about the current situation and future pathways for a comprehensive and integrated cancer control in the region. Childhood cancer was discussed as an integral part of the cancer portfolio.

Dr. Marcela Zubieta, CCI Board Member and Vice President of Fundacion Nuestros Hijos Con Ninos Cancer was among the selected regional leaders for the Latin America Cancer Control Leadership Forum. This was sponsored by the National Cancer Institute (NCI) and the National Cancer Institute of Mexico (INCAN) in association with Pan American Health Association (PAHO), Latin American and Caribbean Society of Medical Oncology (SLACOM), the Network of National Cancer Institutions of Latin America (RINC) and the Union for International Cancer Control (UICC). This project will enhance the capacities of the 7 participating LATAM countries to initiate or improve development of cancer control plans and its implementation, through a multi-sectoral and multi-stakeholder approach. It is an 18 month project and presents a valuable opportunity for participating countries to develop a joint platform to advance cancer control (including childhood cancer) in the region.

### Oceania

The collaborative outreach program for the Pacific Islands of CCI Oceania, headed by Simon Lala and The New Zealand World Child Cancer Charitable Trust (TNZWCC; which he concurrently chairs) have continued to expand and gain ground. The campaign for Early Warning Signs was initiated in Tonga and Samoa. The mentoring of the parent groups that have been previously established there are continuing as well.

TNZWCC has also finalized an agreement with the Fiji Health Ministry for the employment of an Outreach Nurse to be funded by NZ World Child Cancer. Funding will also be made available for the establishment of a Pacific Child Cancer Registry. Twinning between the healthcare professionals in the Pacific and the NZ doctors also continues. The current focus is on reviewing the palliative care needs of the children/adolescents with cancer and their families, in the Pacific Islands.

The Pediatric Cancer Unit at Port Moresby General Hospital in Papua New Guinea has also been given educational and learning materials by the Royal Children's Hospital in Melbourne. This is meant to enrich and enhance their learning initiatives.

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## *Celebrating our Victories*

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### Asia

Poonam Bagai, Founder and Chairperson of CanKids, KidsCan and a cancer survivor herself, was one of 10 non physicians honored by the Indian Academy of Pediatrics for her contribution to child health in India. In her acceptance speech, she said, "We are committed to making a change for childhood cancer in India. Our children must have the same survival rates as anywhere in the world. They deserve

a childhood which is joyous, pain free and a celebration, no matter what. Through our international organization CCI, we work alongside other parent and survivor organizations to bring this change to childhood cancer worldwide."

**In Iran**, MAHAK's website won the first place awards for operating the best non-governmental website. This was announced during the Iran Web Festival. The main focus of this festival was to improve the process of content development in cyberspace and in the field of information technology coherent to Iranian culture. During this festival, which joined The World Wide Web Consortium, 12,000 organizations participated and were evaluated by more than 4,500 related expert juries.

**In Vietnam**, Ms. Kazuyo Watanabe, CEO & Founder of Asian Children's Care League (ACCL), Japan, received the Medal for People's Health from the government of Vietnam. This was in recognition of her long-term supportive contributions to the development of Vietnam's health through the collaborative childhood cancer project with Hue Central Hospital. She received the award on the occasion of the 120th anniversary of the establishment of Hue Central Hospital in December, 2014.

In Japan, Gamaliel James Auste, teen brain cancer survivor and founder of the Cancer Warriors Foundation Philippines and ACCL Founder & CEO Kazuyo Watanabe received front page coverage in Japan's leading daily newspapers, the Nikkei and the Yomiuri Shimbun for their Hope for Kids with Cancer Message during the 42K Tokyo Marathon. This was part of the joint 2015 ICCD celebrations of ACCL and CWFI. The Tokyo Marathon is one of 6 major marathons of the world which James has vowed to complete in order to bring global attention to childhood cancer. To date, James has completed two other prestigious marathons: Chicago and Berlin Marathon, always carrying the banner and message of hope for children/adolescents with cancer.

### Latin America

Nuestros Hijos Foundation was awarded by Chile Fund against Hunger and Poverty for the execution of the project Implementation of Palliative Care Program and Pain Relief for Children with Cancer in Latin America, Bolivia, Peru, Paraguay and Colombia. This program seeks to provide theoretical and practical tools in order to support the implementation of a palliative care program to improve the quality of life and decrease the economic and emotional impact within families.

The Chile Fund against Hunger and Poverty was established by the Government of Chile and the United Nations Development Program (UNDP) in order to promote Chile's international cooperation policy through the creation and implementation of a fund to fight hunger and poverty, in accordance to Chile's commitment to the United Nations Millennium Development Goals.

# Advancing Childhood Cancer Agenda

## **A Major Milestone in CCI's International Advocacy Work was the Convening of the FIRST World Health Assembly (WHA) Side-Event on the Global Challenges of Childhood Cancer.**

Under the leadership of Dr. Oleg Chestnov (WHO Assistant Deputy General for Non-Communicable Diseases), with support from four endorsing countries (namely, the Russian Federation, the Federal Republic of Germany, the Republic of Ghana and the Republic of the Philippines), and in collaboration with SIOP, the breakthrough side-event initiative took place on May 18th, during the 68th World Health Assembly (WHA).

A huge turnout with more than two hundred individuals in attendance, distinguished, highly renowned speakers and high social media presence, marked the success of this side-event.

Speakers were from three key cancer related resource institutions: IARC (International Agency for Research on Cancer), EMA (European Medicines Agency) and the German Cancer League. The Ministers of Health and their teams from the four countries were also personally present. They shared progress and advances made in the implementation of best practice childhood cancer national models which have contributed to improved access to care and reduced childhood cancer mortality and morbidity. They also recommended solutions and future pathways to overcome barriers that limit access to affordable care and services for children with cancer and survivors of childhood cancer.

Representing the CCI parents and all parents of children/adolescents with cancer was HRH Princess Dina Mired of Jordan who delivered a moving inspirational message, challenging everyone to make childhood cancer dialogue “not just a side event, but a major event.” She also encouraged everyone to DO SOMETHING and DO MORE for children with cancer, the survivors and their families.

Dr. Greg Aune, a U.S. based childhood cancer survivor himself as well as a pediatric oncologist and clinical scientist, who is part of the President Obama “Precision Medicine Dream Team” was the voice of CCI survivors and

all other survivors. He reminded the attendees that, “The world loses more than a life when a child dies from cancer. Countries are deprived of future citizens that approach life and see the world from a unique perspective. Losing a child to cancer not only devastates families, it deprives the world of an individual that has endured a unique life experience that propels them to live life giving back. By not doing absolutely everything we can to save children

***Across the continents, CCI Member Organizations have helped to mobilize and secure passage of landmark national laws and legislative issuances. They have also mobilized support to ensure better access to care and improved availability of essential childhood cancer drugs.***

afflicted with cancer, we may be depriving the world of our next great leader, philosopher, doctor, scientist, or artist...” He then made an appeal that, “We can do better. We must do better. It is in fact our duty.”

### **North America: Mobilizing Resources for Childhood Cancer**

**In the USA**, working alongside the Congressional Childhood Cancer Caucus, the American Childhood Cancer Organization, the Alliance for Childhood Cancer and other childhood cancer organizations wrote the Childhood Cancer STAR (Survivorship, Treatment, Access and Research) Act. This legislation, introduced in both the House and the Senate, is focused on increasing childhood cancer funding in order to maximize research, enhance survivor's quality of life and increase access

to life-saving treatments. Senator Reed, the sponsor of the bill states, “Too many young people’s lives have been cut short by cancer. These kids and their families who’ve battled this disease inspire us to take action. The **Childhood Cancer STAR Act** will help young cancer patients and their families get access to potentially life-saving treatments, support survivors, and move us another step closer towards our goal of ending pediatric cancer.”

## Europe: Driving Policy Change

To coincide with this September’s Childhood Cancer Awareness Month, a new pan-European parent-led movement has been formed by a number of European CCI member organizations (Unite2Cure [www.unite2cure.org](http://www.unite2cure.org)). They are uniting in recognition of the fact that the challenges in developing new drugs are multi-faceted, cross country borders and progress will only be made by working in solidarity.

Unite2Cure has issued proposals for a specific set of reforms to current European laws. Called, “Making the European Paediatric Medicines Regulation Work for Children and Teenagers with Cancer” it is premised on the fact that childhood cancers are different from adult cancers. If adopted, these proposals can transform the landscape for drug development for young people with cancer. An innovative aspect of this advocacy is the proposal that every time a drug company develops a new treatment for adults, the drug’s potential for combating childhood cancer in children and adolescents should be investigated leading potentially to new drugs being developed that will target the unique treatment needs of childhood cancer.

A breakthrough document, the European Cancer Plan for Children and Adolescents has also been completed, in part due to the strong collaboration among CCI, SIOP-E and other EU stakeholders. The European Cancer Plan for Children and Adolescents enshrines the long-term vision of the entire childhood cancer community. It seeks to increase the cure rate, eradicate inequalities in access to treatment, care and expertise, boost innovation in medicines development, improve the quality of survivorship, and continue to foster multi-stakeholder dialogue and cooperation for the best outcomes. In November, together with the Members of the European Parliament Against Cancer (MAC), this plan will be unveiled in the EU parliament and shared with the public.

Last February, on the occasion of ICCD 2015 celebration, CCI and SIOPE, together with more than 80 childhood cancer survivors and parents, healthcare professionals and representatives from key European institutions, had a dialogue with the EU Parliament (Brussels). The conversations and presentations revolved on the projected consequences of the new EU Data Protection Regulation on childhood cancer research.

Last March, Prime Minister François Hollande of France, signed into law the “Right to be Forgotten.” CCI member organization Union Nationale des Associations de Parents d’Enfants Atteints de Cancer ou Leucémie (UNAPECLE), a national network of 40 organizations, successfully shepherded this advocacy. The law benefits all patients treated for cancer before the age of 15. Because of this law, whoever declares that they were treated for cancer before age 15, will no longer be required to give additional information. Neither will they have to pay a higher premium or insurance rate. This right is also available for adults with cancer who are off treatment for more than 15 years. In addition, there is also a list of very specific cancers which are commonly considered as completely cured, after only 3 or 5 years.

In **Lithuania**, CCI Member Association “Paguoda” has provided insights and inputs in the development of the Law on Ethics of Biomedical Research Act No. VIII - 1679 at Seimas, which has provisions on the involvement of children in biomedical research. Paguoda initiated a meeting with the Children’s Rights controller E. Žiobiene and Ministry of Health representatives. They also brought up these issues on key committees such as the Seimas Labour and Social Affairs, Health Affairs, Human Rights and Legal committees.

In **Belgrade**, Serbia, the National Association of Parents of Children with Cancer (NURDOR), as part of its ICCD celebration, successfully managed to have childhood cancer integrated in the Minister of Health Ministerial Statement to the Nation. It is also collaborating with a number of stakeholders for the passage of a law increasing the benefits of families with children/adolescents with cancer. This involves extending the sick leave of parents during their childrens’ treatment, to at least 4 months. The proposal has entered the Parliament procedure and awaits listing in the parliament agenda.

## AFRICA: Creating a Supportive Environment for Better Access to Childhood Cancer Care

Not all governments in Africa provide free medical treatment and care for cancer patients. Thus, in countries where cancer treatment is not offered free to patients, CCI members are campaigning vigorously for this to be made available to all children.

Increasingly, more countries in Africa are reporting the support of high profile patrons who influence national policy makers to improve the quality of childhood cancer care that are available. There are also a growing number of First Ladies in Africa who are making time to be with children with cancer and have supported programs and services for children with cancer.

A noteworthy and successful collaborative advocacy intervention has been reported in Ghana by long time CCI Member, Ghana Parents Association for Childhood Cancers (GHAPACC). Through their leadership and persistence, the National Health Insurance has now included a limited number of drugs for childhood cancer.

**In Tanzania**, Tumaini la Maisha is advocating for collaboration between Muhimbili National Hospital (MNH), where all childhood cancer cases are currently being treated and two other large medical centers, Kilimanjaro Christian Medical Centre (KCMC) in Moshi and Bugando Medical Centre in Mwanzathese. This will open the way for establishing two more paediatric oncology centres which will increase access to quality care and reduce travel time to the sole pediatric oncology centre in Dar Es Salaam (MNH).

### Asia: Working Together for Better Access to Childhood Cancer Care

**In the Philippines**, Cancer Warriors Foundation is spearheading the formulation of a national law and/or sub national legislative issuances on Conquering Childhood Cancer. This will involve the multi-stakeholder and multi-sectoral coalition that had previously successfully moved for the inclusion of childhood cancer drugs in the Cheaper Medicines Law (2009) as well as the development of expanded social health insurance coverage for children/adolescents with cancer. It is also leading the building of a multi-stakeholder platform among ASEAN Parliamentarians and Ministers of Health on strengthening access to better childhood cancer care and more affordable treatment in ASEAN countries.



## CCI Survivors Network INFORM, INSPIRE, ENERGIZE ...INITIATE

The CCI Survivors Network seeks to strengthen the voice of survivors and survivor groups worldwide on important issues faced by childhood cancer survivors. By bringing together and connecting childhood cancer survivors, survivor organizations and groups, CCI Survivors Network aims to further expand the collaboration of childhood cancer survivors around the world. It also enables sharing of resources, experiences and information among childhood cancer survivors groups, associations and organizations everywhere in the world. The network also provides guidance and assistance in the establishment of childhood cancer survivor groups and survivor mentoring programs as well as works with representatives of other survivor associations to inspire and help enhance their capacities.

The CCI Survivors Network Executive Committee is composed of Michaela Willi, Sabine Karner (Austria), Meike Naafs and Jaap den Hartogh (the Netherlands). Patrick Yip from Hong Kong is the newest member.

As a result of the Asia CCI Regional Conference in Amman, Jordan (April, 2015), a Survivors Working Group for Asia has been formed. The initial team is composed of four survivors, from member organizations in Asia (Patrick, PKW, Hong Kong; Ramez, CHANCE, Lebanon; Zeina, KHCC, Jordan and Kapil, CanKids KidsCan, India) who attended the Jordan conference. The Working Group, named CCI Survivors Asia (CCISA) has two major goals: 1/ To build connections and enhance relationships among childhood cancer survivors from Asia and 2/ To improve awareness and understanding of childhood cancer survivorship realities, issues and challenges. The first project of CCISA will be establishing a gathering place through a Facebook page. They will also be developing a video capturing survivors' feelings and insights about their childhood cancer journey and what it means to be a survivor.

In the recent 2015 CCI Europe meeting in Malmö, Sweden, there was a survivors' session for twenty eight participating survivors. For most survivors, this was their first survivors meeting. Three breakout discussions groups, led by Aimilia Tsirou, Zuzana Tomasikova and Sabine Karner discussed topics such as long-term follow-up, survivors associations and education/training for survivors. A wonderful video clip created by Neira Kamerik, in which the participants expressed their views on survivorship, summarized and closed the session.

# Building & Enhancing Capacities

## 2015 Regional Conferences, Publications and Learning Materials.

As part of its commitment to continuous enhancement of member's capacities, CCI sponsors annual regional conferences across 3 continents (Asia, Latin America and Europe). CCI-Africa holds its regional conference every two years. This year saw a noticeable increase in the number of participants and/or countries attending the regional conferences.

In addition to these, CCI member organizations also sponsor their own local /national conferences, meetings, forums and dialogues. The list of this can be found in the CCI website.

### Latin America: Sharing and Learning Together

The 2015 CCI LATAM Conference was held in Luján, Buenos Aires, Argentina from 17th to 20th of March. More than seventy (70) representatives, of forty (40) Childhood Cancer Organizations, from seventeen (17) Latin American countries were in attendance.

The conference was organized by CCI Argentina member, Natalí Dafne Flexer Foundation, in collaboration with the CCI LATAM Regional Committee. Discussions revolved on psychosocial support programs for families, fertility issues among childhood cancer survivors, bio-molecular advances in drug development and treatment of childhood cancers and pediatric palliative care. There were also sessions on organizational development, resource mobilization, national level networking and alliance building.

Given the number of countries present,

the conference provided an opportunity to do a review of the childhood cancer situation and challenges across participating countries. It revealed significant differences on the level of assistance and coverage for kids with cancer in LATAM. It also detected inequalities in access to treatment and care not only in the different countries but even among different regions and cities of each country.

The importance of collaboration among all CCI member organizations and other stakeholders was seen as a way to achieve equity across LATAM. Experience sharing and provision of technical guidance and support between robust, well-developed organizations and those still in need, was agreed upon as a necessary forward action.

The closing ceremony had the theme Protecting and Promoting the Rights of Children and Adolescents with Cancer in Latin America. The CCI Board of Trustees (who were also in Argentina for their mid-year board meeting) attended the closing ceremony. Representatives of the Argentinian Health Ministry, the National Cancer Institute, OPS in Argentina, Directors of different public hospitals and Buenos Aires City authorities were also on hand to show support and express their commitment for ensuring rights and needs of children and adolescents with cancer were met.

The Situational Analysis and Proposed Actions will be detailed in a document at the CCI LATAM Regional site: [www.cancerinfantillatinoamerica.org](http://www.cancerinfantillatinoamerica.org)

### ASIA: Inspiring and Catalyzing Action

In April, the 9th Asia Regional Meeting was held in Amman, Jordan. The theme was both a challenge and a vision: "Towards Better Cancer Care for Children of Asia and the World."

The conference was under the patronage and generous support of HRH Princess Dina Mired, the King Hussein Cancer Foundation (KHCF) and the King Hussein Cancer Centre (KHCC).

Eighty participants from 12 countries in Asia were actively engaged in the plenary dialogues, panel discussions, action clinics, conversation circles and workshops. The active interaction of the survivors both in and out of the sessions, helped plant the seed for the formation of a CCI-Asia Survivors Network. Networking among the participants also led to the formation of virtual communities of interest and communities of practice.

The prominent line up of speakers included: HRH Princess Dina Mired of Jordan, Dr. Maria-Cristina Profill of WHO-Jordan, Dr. SM Moazzem Hossain of UNICEF MENARO Jordan, Dr. Scott Howard of SIOP-PODC and Dr. Purna Kurkure of the Indian Cancer Society. The story and insights shared by HRH Princess Dina in her account of her family's personal childhood cancer journey (Session 1: Role and Challenges of Parents in the Childhood Cancer Journey) resonated with and inspired the participants.

The other major themes for the learning sessions were: Emerging Challenges In Pediatric Palliative Care and Pain

Management for Children/Adolescents with Cancer (Joint WHO – CCI – KHCC Session); Promoting and Recognizing Rights of the Child (in collaboration with UNICEF and SIOP-PODC); Expanding Stakeholder Engagement: Alliance Building & Networking, Increasing Childhood Cancer Awareness & Mobilizing Support and Survivor Journeys. There were also free papers on nutrition, dental care and innovative art therapy for psychosocial support. A special session for survivors: Stories of Courage and Hope, gave an opportunity for survivors to retrace and share their personal journeys.

This was the first CCI Asia conference where there were joint sessions with SIOP PODC as well as UNICEF (United Nations International Children’s Fund). This is aligned with CCI’s focus on promoting rights based, child centered and family focused treatment, care and support.

### Europe: Working Together for Sustainable Change

The 2015 CCI Europe Regional Meeting was held in Malmo Sweden from 8-10 May. It was attended by a markedly high number of participants—ninety nine from twenty three countries in Europe. About one third of the participants were attending the CCI Europe Regional Meeting for the first time.

The regional meeting was hosted by CCI Europe Member, the Swedish Childhood Cancer Organization Barncancerfonden Södra, in collaboration with the CCI Europe Regional Committee. This served as a valuable opportunity for parents, survivors and representatives from childhood cancer organizations to get together, exchange information, learn from each other’s experiences and identify pathways for working together.

Dr Gilles Vassal (SIOP-E President) presented the “Roadmap to Horizon 2020 and Beyond” which aims for a sustainable childhood cancer plan in Europe. This roadmap includes seven

medical and scientific objectives for pediatric oncology: improving quality of survivorship, addressing specific needs of teenagers and young adults, introducing innovative treatments (new drugs, new technologies) in multi-disciplinary standard care, precision medicine in health care, increased equal access across Europe to expertise and clinical research, understanding the causes of pediatric cancer and where possible, its prevention. SIOP-E and CCI Europe Regional Committee will be co-operating in the implementation of the European long-term strategic plan and will raise awareness about cancer in children and adolescents.

There were also updates and sharing of insights about the ongoing EU funded projects, like ENCCA, ExPO-r-Net, PanCareSurFup, PanCareLife and IntReALL. You can find more information about the ongoing EU funded projects on the CCI website.

A very engaged discussion and interaction was stimulated by the presentations of Patricia Blanc (F) and Cesare Spadoni (UK) on the urgent need for new drugs in the treatment of childhood cancer. It was agreed that there will be joint actions worked out and presented to the CCI-Europe groups, for driving advocacy in both national and international levels.

Dr. Lars Hjorth, pediatric oncologist and specialist in late effects from Lund University (Sweden) as well as Chair of PanCare, addressed the question: Long Term Follow Up—Where Are We Going? As a result of the session, participants reaffirmed the great need for parents, survivors and health care professionals to work together and advocate for implementation, funding and integration of the survival passport in national health care systems across Europe.

Two survivors from Luxembourg showed four heartwarming video clips which they had produced. These provided fresh insights into cancer treatment and late effects, as seen from a survivor’s

eyes. Sabine Karner shared a special career counselling project for survivors in Austria which will be the basis for a new EU-funded project called “Create your Future.” Caroline Scott, from the well-known Barretstown-Camp in Ireland, presented how research impacts and shapes program development. In 2014 a new program, called “Growing Camp Connections” was developed because of research done by Yale University. The meeting ended with Anne Goeres playing the sample of music composed, played and sung by a group of survivors from Luxembourg. It was a fitting reminder of the essence of CCI EUROPE shared mission and commitments.

***CCI member organizations also spearhead publication of resource books, hand books, informational and learning materials and toolkits.***

The American Childhood Cancer Organization (ACCO) continues to build on its resources that are provided to children with cancer and their families across the U.S. This past year they published a comprehensive resource entitled, A Parent’s Guide to Enhancing Quality of Life in Children with Cancer. This book is the only book in the world dedicated to pediatric oncology palliative care.

ACCO also proudly released their medical play therapy kit. Designed to educate and empower the child undergoing cancer treatment, the kit includes real medical devices including stethoscope, central line catheter, thermometer, surgical gloves and other educational items. More than 1,000 requests for this resource were received within the first 10 days of its release, bringing a total of 45,095 free resources distributed to families across the U.S in the past year.

**In Canada**, the Kids with Cancer Society of Northern Alberta, has focused on creating a program and learning activities that addresses the educational needs of children who are experiencing challenges related to treatment.

In Europe, the “Guide in Early Diagnosis of Childhood Cancer” intended for pediatricians and general practitioners, was launched as part of the ICCD celebration in Spain. It is the result of a collaboration between the Spanish Federation of Childhood Cancer Parents (FEPNC), SEHOP (Spanish Society of Pediatric Hematology-Oncology), AEP (Spanish Association of Pediatrics) and AEPAP (Spanish association of Primary Care Pediatrics). This follows the launch of the highly successful Clinical Practice Guideline for Pain Management in Children with Cancer which was produced in collaboration with the Fundacion Cris Contra el Cancer and the Federacion Espanola de Padres de Ninos con Cancer, in 2013.

**In India,** CanKids, KidsCan, launched as part of its focus on nutrition, a guidebook and a menu book. It also has a tool kit which serves as a guide on establishing parents homes or transition housing for families whose

children are under treatment for childhood cancer.

On the occasion of the launch of the ACT NOW campaign, CCI-Global developed and disseminated the RIPPLES Advocacy Tool Kit. It also developed (in collaboration with SIOP PODC) the advocacy material 8 Reasons Why Childhood Cancer should be a Global Child Health Priority and the awareness material/infographic on Facts and Myths on Childhood Cancer. For International Childhood Cancer Survivors Month, a new set of Facts and Myths on Survivorship was developed and released. These are all found in the website, [www.internationalchildhoodcancerday.org](http://www.internationalchildhoodcancerday.org).

For ICCD, CCI in collaboration with UICC and SIOP also developed posters for public awareness campaigns and pocket cards, with key early warning signs on childhood cancer. This was for use as guide and quick reference

materials by health care professionals in primary health facilities. The materials have been translated into over 40 languages and used in many different countries and settings around the world. A number of CCI members continue to scale up distribution and use of these materials for this years ICCD campaign.

2015, which is year two of this campaign, saw the release of ‘talking head videos.’ These were narrated by doctors, a nurse, a cancer survivor and a parent and were expected to contribute to increased early diagnosis by primary health care professionals or timely referral by community volunteer health workers.

For the World Health Assembly, CCI in collaboration with the SIOP Advocacy Team, developed an issue briefer on Global Challenges of Childhood Cancer. This can be found on the CCI website.



# Act Now for Kids with Cancer

## A Global Alliance to Ensure Better Access to Care for Children and Adolescents with Cancer, Everywhere.

We are very proud of what you all have managed to achieve for this campaign in terms of creating awareness, increasing visibility for childhood cancer messages, engaging new partners/stakeholders and mobilizing support for your local childhood cancer initiatives. We are hopeful that this will propel the whole community to strongly advocate and demand for the BEST for children and adolescents with cancer through:

- Better access to childhood cancer treatment and care;
- Enhanced availability and access to affordable and/or free essential childhood cancer medications, including those for pain treatment;
- Social protection through inclusion of childhood cancer in social health insurance or universal health coverage;
- Stronger paediatric palliative care;
- Targeted, less toxic treatments developed and approved, leading to decreased chronic late effects for survivors of childhood cancers.

On the occasion of the 13th International Childhood Cancer Day celebration, CCI created and launched the global campaign ACT NOW. The 2015 ICCD campaign was a local and global call for solidarity in action: Joining Voices, Connecting Forces and Consolidating Initiatives when responding to the needs of children/adolescents with cancer, their families and the survivors.

We urged governments as well as international development organizations and its various agencies, to work together with parents and survivor groups, non-government organizations, civil society organizations (e.g., medical practitioners, health workers, academia, faith based organizations, sectoral groups) private sector and business groups to make childhood cancer a public health priority.

The IPA message of solidarity was: “We at the International Pediatric Association (IPA) proudly proclaim our readiness and willingness to “STAND UP and SPEAK OUT” for kids with cancer, the survivors and their families). The IPA wholeheartedly declares its solidarity in supporting the organization’s unified message and ultimate goal in making childhood cancer a greater public health priority. The IPA shares in CCI’s core belief that “every child with cancer

deserves the best possible medical and psychosocial care, regardless of country of origin, race, financial status or social class. Let February 15th 2015, International Childhood Cancer Day, be a day that influences both awareness and attitudes in engaging the fight against childhood cancer!”

In the ICCD website, there was a One Voice section where Global Child Health Prime-movers and luminaries expressed their thoughts, gave messages and shared opinions on how to overcome the challenges posed by childhood cancer.

Dr Oleg Chestnov, Assistant Director-General for Non-communicable Diseases and Mental Health in the World Health Organization had the following inspiring message.

***“The majority of children with potentially curable cancers can get cured even in low-resource settings, and all children with advanced cancer can benefit from pain relief and palliative care. Children’s rights cannot be fulfilled and protected unless preventing and treating cancers is included as a priority within national cancer control programmes. Together with NGOs such as Childhood Cancer International (formerly ICCPO), WHO is strongly committed to supporting national efforts to control childhood cancers in low- and middle-income countries and to reach all children in need, wherever they are excluded and left behind. If we overcome the barriers that have kept these children from the services that they need and that are theirs by right, then more will grow up healthy and realize their full potential.”***

Other luminaries in the ONE VOICE page included Former President George and Barbara Bush, USA, Sir George Alleyne, Director Emeritus, Pan American Health Organization (PAHO), Dr. Andrew von Eschenbach, 12th Director of the United States National Cancer Institute, Congressman Michael McCaul (R-TX) and Congressman Christopher (Chris) Van Hollen (D-MD), Co-chairs, Congressional Childhood Cancer Caucus, U.S. House of Representatives, Sr. Jesús González Marín with his son Jesús (1981-1989), First Chairman of ICCPO Board of Trustees,

Marianne Naafs-Wilstra, Past Chair and Founding Chair, ICCD, Dr. Tezer Kutluk, President, Union for International Cancer Control (UICC), Dr. Giorgio Perilongo, President, Society of Paediatric Oncology (SIOP), Prof. Andreas Konstantopoulos, President International Pediatric Association (IPA), Dr. William J. Keenan, Executive Director, International Pediatric Association (IPA), Seun Adebisi, JD, NCD Child Advisory Council, Dr. Peter C. Adamson, Chair, Children's Oncology Group, Dr. Gabriele Calaminus, Head of SIOP Global Advocacy, Immediate Past-President, SIOP, Dr. Gregory H. Reaman, Associate Director, Office of Hematology and Oncology, U.S. Food and Drug Administration.

The Chair of the Children's Oncology Group (COG), Dr Peter C. Adamson mirrored the thoughts and feelings of many parent worldwide.

***“Despite the progress we have made in improving the outcome for children with cancer through research, we must devote a renewed sense of urgency to developing more effective and less toxic treatments for all children with cancer. Too many of our children must endure months to years of chemotherapy, radiation therapy and surgery, and for those children whose treatment does afford “cure,” the long-term effects of cancer and its treatment can be significant. We must accelerate our research efforts and deliver better outcomes to children and families through increased research support and stronger partnerships with government funding agencies, biopharmaceutical companies, regulatory agencies and academic medical centers. Our children deserve nothing less.”***

**In United Arab Emirates**, Sheikha Jawaher bint Mohammed Al Qasimi, wife of the Ruler of Sharjah, founder and Royal patron of the Friends of Cancer Patients Society (FoCP), called on the

international community to STAND UP against the increasing number of children dying due to cancer around the world. She emphasized the need for the international community to shoulder its humanitarian responsibility towards these children, especially those who do not have access to specialized clinics or hospitals to provide them with the necessary treatment and medical care.

### **ICCD 2015: Expanded Reach, Increased Visibility, Higher Impact**

The ICCD website, (<http://www.internationalchildhoodcancerday.org>), tool kit (translated into several languages) and social media platforms (Facebook and tumblr: iccdactnow) created a high degree of interest and support for ICCD, both in the virtual platforms and across countries. In collaboration with the SIOP Advocacy team and the technical support of JJ Divino and Dr. Andreas Ullrich, for the first time, the WHO had a dedicated page on ICCD and childhood cancer.

A total of 75 countries reported having ICCD activities in their countries. In some countries in Asia and Eastern Europe, member organizations celebrated ICCD for a whole month so as to maximize reach and media mileage. Commitments were made, resources mobilized and childhood cancer messages delivered with extra impact. Most of these were attended by local dignitaries, health and political leaders, national celebrities and international figures.

**In Italy**, the ICCD celebration hosted by FIAGOP (Italian Federation of Parents Pediatric Oncology), AIEOP (Italian Association Hematology Oncology) and SIAMO (Italian Society Adolescents with Oncology-Hematological Diseases) was capped by a thousand people consisting of children and young adults with cancer, accompanied by their families and volunteers, being received in audience for special blessings by Pope Francis. In the Indonesia ICCD celebration of Yayasan Anyo Indonesia (YAI), the U.S. Ambassador to Indonesia, Mr. Robert O. Blake,

and the Deputy Chief of Mission, Mrs. Kristen F. Bauer and her family, together with a group from the U.S. Embassy attended the event.

CCI member organizations also intensified their advocacy, awareness raising and advocacy initiatives, leveraging the campaign materials provided. They designed special commemorative T-Shirts and other creative promotional collaterals to promote ICCD and the Gold Ribbon.

The Gold Ribbon is the international symbol for Childhood Cancer. Gold is the colour for childhood cancer. It symbolizes how precious and priceless children and adolescents with cancer are. It honours the courage and determination of children with cancer and their families as they bravely struggle with the disease. It reminds us of how we must protect, SPEAK OUT and STAND UP for the lives and futures of children/adolescents with cancer.

**In the United States**, the American Childhood Cancer Organization created a T-shirt with the gold ribbon containing the names of 3,454 children and adolescents with cancer.

**In Japan**, the Children's Cancer Association of Japan printed a green T-Shirt with the message Stand Up and Go Together. They wore this as they distributed 36,000 ICCD information cards in shopping malls, temples, subway stations, hospitals, government buildings and streets. The ICCD campaign of CCAJ received prominent coverage in the Mainichi Shinbun newspapers across the prefectures (e.g. Kyushu, Fukui, Kyusyu etc.) as well as the Niigata Nippo and major TV, Radio Networks. To promote the gold ribbon, CCAJ distributed 17,000 packets of pocket tissue with the message of “A Gold Ribbon With You.”

**In Kenya**, Africa, the Hope for Cancer Kids promoted the Act Now message by making available T-shirts with this message. It was a very popular and saleable item. They also partnered

with the Kenya Medical Association, for a series of interactive events including a 5Km walk to raise awareness of childhood cancers; a free basic screening which was done by Moi Teaching and Referral Hospital (MTRH) and The Aga Khan Hospital and fun and games for families and supporters. Dignitaries and doctors from the Kenya Medical Association (KMA), Kenyatta National Hospital Oncology Unit and Kenya Medical Training Institute Principal gave messages. Two prominent pediatric hematologists Dr. Jessie Githanga and Dr. Rajab attended and asked to be included in other upcoming events. The event was given wide media coverage before and after the event.

### ICCD 2015 was a Day of Solidarity and Innovations

**In Italy**, in a unique display of solidarity, on February 10 at 11:00 in the morning, through the involvement of every territorial member associated with FIAGOP, there was a simultaneous launching of 8000 balloons in hospitals, squares and schools across 21 cities of Italy (Bari, Beilla, Bologna, Cagliari, Catania, Cosenza, Florence, Genoa, Lecce, Messina, Modena, Monza, Naples, Palermo, Parma, Pescara, Pisa, Rieti, Rome, Rimini and Udine).

**In South Africa**, Cape Town's iconic Table Mountain, one of the Seven Wonders of the World, was lit up in blue on Valentine's Eve and into the early hours of the morning of the 15th. This mind-blowing event was organized by CHOC—Childhood Cancer Foundation. The lighting of the mountain created a stir in the media with many radio and some television interviews with CHOC staff, a pediatric oncologist and a childhood cancer survivor. This year the focus of ICCD was to create awareness of the need for early detection and diagnosis of childhood cancer and to make people aware of the early warning signs. People were encouraged to wear blue because CHOC's logo has blue.

### Childhood Cancer Survivors Week: Learning to Dance in the Rain

Since 1988, there has been a National Cancer Survivors Day celebrated initially in the USA and over the past years, in other countries. It initially was commemorated as June 4th but is now celebrated on the first weekend of June. However, there has not been a survivors day focused on survivors of childhood cancer.

This year, as part of the ACT NOW Campaign, and to reinforce our message that many childhood cancers are curable with early diagnosis, proper treatment and adequate/appropriate treatment, care and support, CCI launched the First International Childhood Cancer Survivors week with the participation of SIOP Advocacy and SIOP PODC leadership teams as well as UICC. SIOP PODC and UICC teams contributed to the finalization of the material: "Myths and Misconceptions on Childhood Cancer Survivorship."

This was translated and transformed into infographics, tweets and social media messages. UICC complimented the CCI social media platform for this event (Facebook page: childhoodcancersurvivor journeys).

**HRH Prince Azim Bolkiah of Brunei**, shared a very moving and inspirational message on the childhood cancerjourneys Facebook page. His message was, ***"Life is not about waiting for the rain to stop, but learning to dance in the rain." I don't quite see myself as an inspiration, though I can help these children learn to dance in the rain, but it is the parents, the carers (i.e., the wonderful people we have in RIPAS who help these children) and other cancer survivors who prove that there is hope and light beyond the tunnel, who are the inspiration. Each individual who has a family member or friend battling childhood cancer has a role to play. Each individual has the ability to lighten up these kids' day and make them see the beauty of life, make them feel encouraged to continue having dreams and aspirations. Every person has the power to inspire. Though it may be difficult, sometimes we do have to be positive and see the rainbows rather than the rainstorms. Everyday is different, everyday may be an uphill battle that may seem endless and thankless, but to be able to show these children that blue skies and butterflies are gifts and make them feel the grandness is, I think, paramount in giving them the strength that they may need to heal.***

***Since it is also International Childhood Cancer Survivors Month this June, I would like to say to all the survivors: Here's to hope, to dreams, to the future. Shine brighter, smile wider and love bigger. Continue to show the world that there is beauty in this life. It is our hearts and our spirit, and all of you are living proof!"***

***All my love,  
Azim Bolkiah***

CCI member organizations in a number of countries held "reunions" and special events for survivors and their families. There were also successful advocacy related initiatives for increased/improved government assistance, programs and services for survivors, as well as more robust survivor follow-up care programs. Through these celebrations, CCI across the globe, raised the profile and made visible the stories of our survivors; capturing their courageous journeys, highlighting their challenges and concerns as well as their dreams. Through these initiatives, we successfully spotlighted the message that childhood cancer survivors are the faces of our future; they are priceless, irreplaceable shapers and movers of our shared future. We need to ensure there is continuing care for them.

### September 2015 Launched “Light Up Hope, Light It Up Gold Campaign!”

In September, CCI spearheaded the last event in the ACT NOW campaign, The “Light Up Hope, Light It Up Gold Campaign.” This was launched during International Childhood Cancer Awareness Month. In collaboration with many parent groups all over the world and with the help of our tireless and dedicated volunteer Tribute Lighting Coordinator, Neal Rourke (a bereaved father himself), more than 150 iconic and natural landmarks, monuments, buildings and bridges have now gone gold all over the world. These can be viewed on CCI’s website and American Childhood Cancer Organization’s website at: <http://www.acco.org/light-up-the-world-gold>.



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PRINTING OF THIS CCI ANNUAL REPORT IS SPONSORED BY  
PAU KWONG WUN CHARITABLE FOUNDATION, HONG KONG.