



Childhood Cancer International

2016

ANNUAL REPORT

**ADVANCING CURE,
TRANSFORMING CARE
FOR CHILDREN WITH CANCER,
SURVIVORS,
AND THEIR FAMILIES**



CHILDHOOD CANCER IS CURABLE!

if diagnosed early and given appropriate treatment and care. In developed countries, approximately **80%** of children with cancer achieve long-term survival. However, in low and middle-income countries (LMICs), despite progress achieved to date in some settings, survival rates are dramatically lower, ranging from a low of **10%** to an average of **60%**.

80% of children and adolescents with cancer, live in low and middle-income countries where access to quality care is limited and chances of a cure are poor.

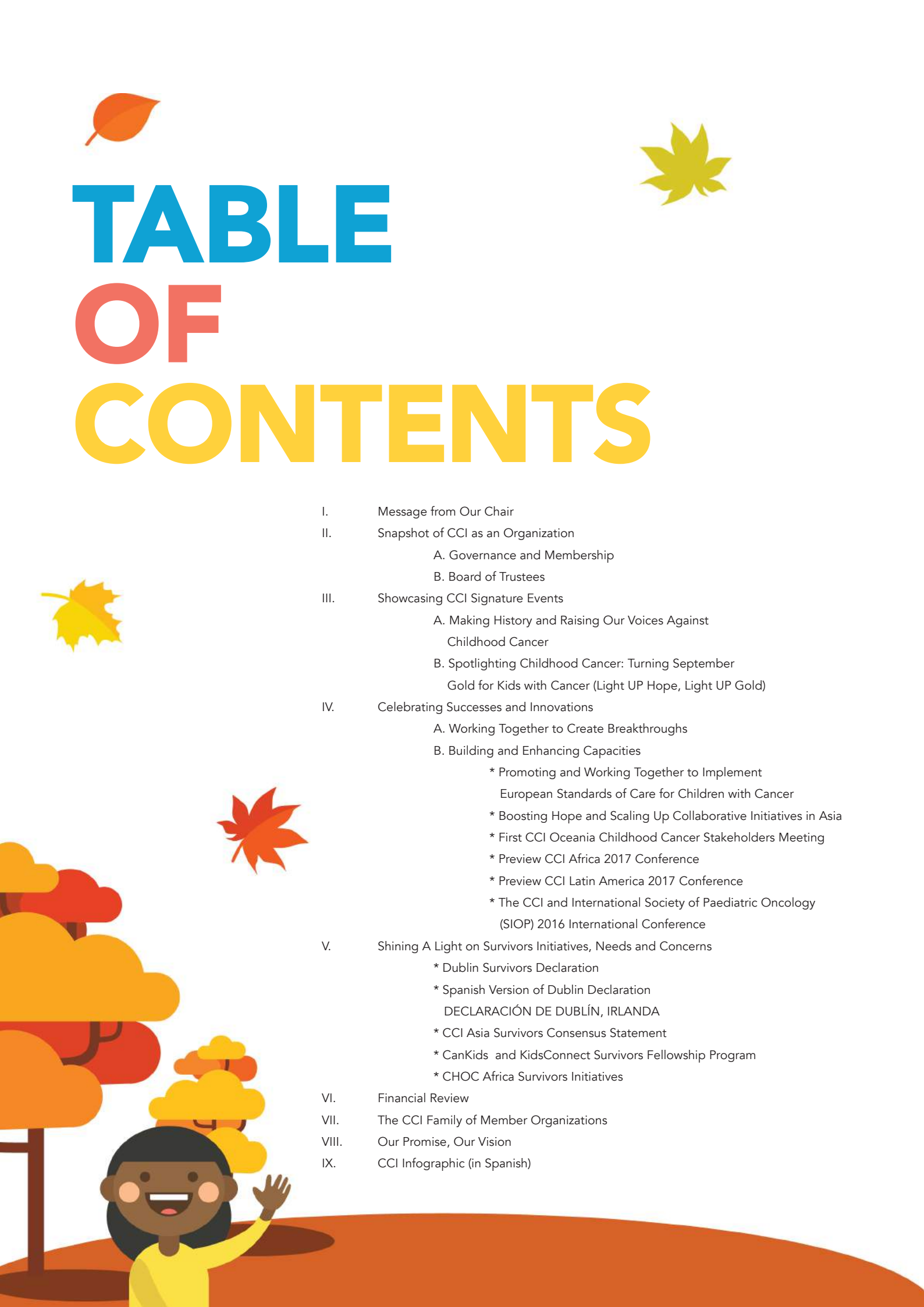


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OUR PURPOSE AND FOCUS

**Create breakthroughs,
transform childhood
cancer care, advance cure
for all childhood cancers
and build a caring community
of support for children/
adolescents with cancer,
the survivors and their families.**

WHO ARE WE

We are the collective voice of parents groups, survivor associations, national organizations and childhood cancer support organizations.

WHO DO WE WORK WITH

We engage and collaborate with diverse stakeholders: policy makers and influentials, international development practitioners, medical and healthcare professionals, public and private sector and civil society.

WHAT DO WE DO

Driven by passion, determination and caring for others, we advocate and support programs and services to improve access to affordable, essential childhood cancer medicines and high quality childhood cancer care everywhere.

We promote dialogue, knowledge sharing, innovations and good practice models, to responsively address challenges faced by children/adolescents with cancer, the survivors and their families.

**TOGETHER, WE WILL TRANSFORM
CHILDHOOD CANCER CARE, EVERYWHERE.
TOGETHER, UNITED, WE ARE STRONGER.**

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MESSAGE FROM OUR CHAIR

2016 has been described by historians and global watchers as the beginning of a time in the world's history, marked by intense volatility, uncertainty, chaos and anxiety. In the midst of all these, it is good to know that CCI and its members experienced a period of remarkable growth, innovation as well as significant achievements which has continued on to 2017.

We were able to scale up our international network of collaborating allies and partners, nurturing closer relationships and undertaking groundbreaking shared initiatives, globally and locally (SIOP, SIOP E, SIOP PODC, UICC, NCD Child, Children Living Among Neighbours, Australia, ICPCN (International Children's Palliative Care Network), International Pediatric Association (IPA), IAEA (International Atomic Energy Agency), Maruzza Foundation, St. Jude's Children's Research Hospital, St. Baldrick's Foundation, The Max Foundation, Universal Health Care Alliance).

We deepened and intensified our engagement with the World Health Organization through collaborative country level work in Ghana, Ethiopia, Myanmar and Fiji. We have planted seeds for future shared local initiatives in Asia, Africa and Latin America, where 80% of children/adolescents with cancer live and where the projected substantive increase in childhood cancer incidence is expected in the next 10-15 years. CCI is also a key member of the WHO Global Childhood Cancer working group.

Regionally and nationally, an increasing number of our members have strengthened their collaborative endeavours with governments, civil society and international development institutions. Assisted by advocacy and awareness building campaigns CCI has designed and inspired by best practices learned through member interactions, there has been a flourishing of new initiatives and a visible dynamism. This is at the heart of making visible the issues and needs of children/adolescents with cancer, the survivors and their families. It will help create a highly supportive and enabling environment for children/adolescents with cancer, survivors and their families. All these are essential to making childhood cancer a priority in both global and national health and development agendas.

As part of being a learning organization and to further catalyze growth of our members, we created a platform for coaching and collaboration among CCI members in various regions, who are in differing stages of development. Through this mechanism, CCI anchor organizations will be able to share their distinctive competencies and strengths with other CCI members who are emergent or still developing. Beacon organizations will assist and provide financial support to CCI and the resource challenged CCI members. It has been said that real generosity towards the future lies in giving all to the present. This year, responding to the call #Together4Kidswithcancer, DO MORE



- BE MORE for children/adolescents with cancer, survivors and their families, we saw a number of member organizations volunteering/sharing their staffs time and talents and/or sharing resources to assist CCI in effectively pursuing its mission and goals. We also noted an increase in cross-country joint initiatives among CCI member organizations in all continents.

Indeed, "We Care – We Share" and "Together, Stronger" are no longer just inspirational words – it has become a norm, a standard practice, a way of life.

Innovative strategies and approaches led to transformative breakthroughs and significant achievements which contributed to more responsive programs, projects and services for children/adolescents with cancer, survivors and their families. New program and service pathways in palliative care and pain management, nutrition, education, psychosocial support, advocacy, networking and alliance building were developed and implemented.

CCI global and local awareness building reached new heights when it leveraged social technology and new media, reinforced by both traditional and community media. In its first month alone, the Child4Child original CCI song We Are One reached more than 350M. Since then, it has migrated from the digital world and serves as an international anthem galvanizing action, mobilizing support, generating increased attention and commitments for helping children/adolescents with cancer, the survivors and their families.

In behalf of the CCI board, the families of the children/adolescents of the world with cancer and the survivors, we extend our outmost appreciation and deep gratitude for all the tireless and selfless work that you continue to do in behalf of children/adolescents with cancer, the survivors and their families. It has been an honour and a privilege to work side by side with you all these past 2 years.

Moving forward, let us continue to work together, creating SUSTAINABLE CHANGE with LASTING IMPACT on the lives and futures of children/adolescents with cancer, the survivors and their families.

CARMEN AUSTE

A handwritten signature in black ink that reads "Carmen".

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 nine years. The Chair and Vice Chair have a three years fixed term of office and cannot be reelected.

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

During the 2016 Annual General Assembly, Jojo Maria de Lencastre de Braganza (Portugal) and Kwame Aveh (Ghana) were both elected for an initial one year term. Luisa Basset (Spain), Mary McGowan (Australia), Poonam Bagai (India) and Marcela Zubieta (Chile), continued their terms while Kenneth Dolman (Immediate Past Chair) entered into his last year of service to the Board. In the current board, Luisa Basset and Poonam Bagai continued in their roles of Board Secretary and CCI Corporate Treasurer respectively.

MEMBERSHIP

CCI represents 183 parents, survivors, family and childhood cancer support and advocacy organizations in 93 countries, across 6 continents. 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 210 organizations. This means CCI represents at least 393 organizations all over the world.

CCI global network includes member organizations from both high resource and resource challenged countries. Europe has 67 members in 33 countries, North America, has six members from 2 countries and Oceania, 4 members from 3 countries. Asia membership is 47 organizations from 22 countries, LATAM, 35 organizations in 17 countries while Africa has 24 members from 16 countries.

The 2016 General Assembly accepted 6 new members– 3 full and 3 associate: 3 were from Europe (2-Slovakia, 1-Ireland) and 3 from Asia (India, Jordan and Thailand). Four organizations from Indonesia terminated their membership due to consolidation with their mother CCI umbrella organization.

HEAD OFFICE

VOKK (CCI member in the Netherlands and a founding member of CCI) hosts the CCI Head Office. Lex Kuiper is the current Finance and Administrative Services Officer. Simon Lala is the Chief Financial Officer and Marianne Naafs-Wilstra is Board Advisor for Governance and Nominations.



Childhood Cancer International represents 183 parents, survivors, family and childhood cancer support organizations in 93 countries, across 6 continents!

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GOVERNANCE AND MEMBERSHIP



BOARD OF TRUSTEES 2016



CARMEN VALLEJO 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 Corporation). Carmen is a social psychologist by profession and has worked in the public policy and program arena for the past 35 years..



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 where none existed before.



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 author/editor of 11 childhood cancer learning resources. She has a Masters in Public Health.



JOˆO MARIA DE LENCASTRE DE BRAGANZA
Member

Joˆo 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..



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 Espaˆola de Padres de Niˆos con Cancer 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.



KWAME AVEH
Member

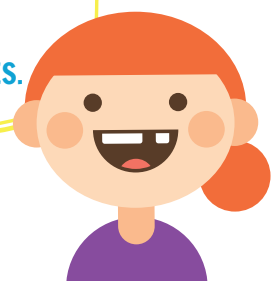
Kwame is the bereaved father of the late master Elorm Aveh who died of leukemia at age 9. Kwame is the Chairman of the Ghana Parents Association for Childhood Cancers (GHAPACC). He is a Chartered Accountant and Development Finance Specialist as well as the Head of Department at the Ghana Institute of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



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.

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



3

MAKING HISTORY AND RAISING OUR VOICES AGAINST CHILDHOOD CANCER



The children of the world were invited to “Raise your voice against childhood cancer” by singing the chorus of the song, **We Are One** and recording it.

Close to a million children all over the world contributed their personalized and creative versions of the song.

A Major Milestone in CCI’s International Awareness Efforts was the Launch of the Global Child4Child Campaign on International Childhood Cancer Day (ICCD) 2016

By the end of the 1 month campaign period, it had generated 365 million loops and 25 million likes in various social media platforms.

International Childhood Cancer Day (www.internationalchildhoodcancerday.org) was first launched by CCI in 2002. It is commemorated every 15th of February to honor the courage, strength and resiliency

of children/adolescents with cancer, all over the world.

On the occasion of the 15th International Childhood Cancer Day (ICCD), Childhood Cancer International, with the initiative of the CCI Europe team (headed by Anita Kienesberger), the creative inputs of the team from the premier Swedish advertising agency Garbergs and the technical support of its member organizations Barncancerfonden (Swedish Childhood Cancer Foundation) and American Childhood Cancer Organization (USA), created and launched the distinctive, one of a kind, child focused global awareness campaign “Child4Child” (www.child4child.com).

This incredible campaign was meant to help raise awareness that kids have cancer too and that other kids can inspire those kids still bravely fighting cancer. It invited and encouraged children all over the world to RAISE THEIR VOICES AGAINST CHILDHOOD CANCER by singing, dancing, miming, acting to the chorus of the song.

Christophe Beck, the composer for Disney’s smash hit Frozen, together with his 12 year old daughter Sophie, wrote a new song “We Are One” capturing the journey and the spirit of kids fighting cancer. A consolidated version of the song was created by David Goldsmith and released on ICCD in more than 50 global music platforms such as Spotify, iTunes, Musical-ly as well as YouTube. Child Ambassadors for this campaign included Livvy Stubenrauch (the voice of Anna in Disney’s Frozen), Alexa Curtis (winner of The Voice Kids Australia 2014), Robbie Firmin (Britain’s Got Talent) and Aaralyn O’Neil (America’s Got Talent).



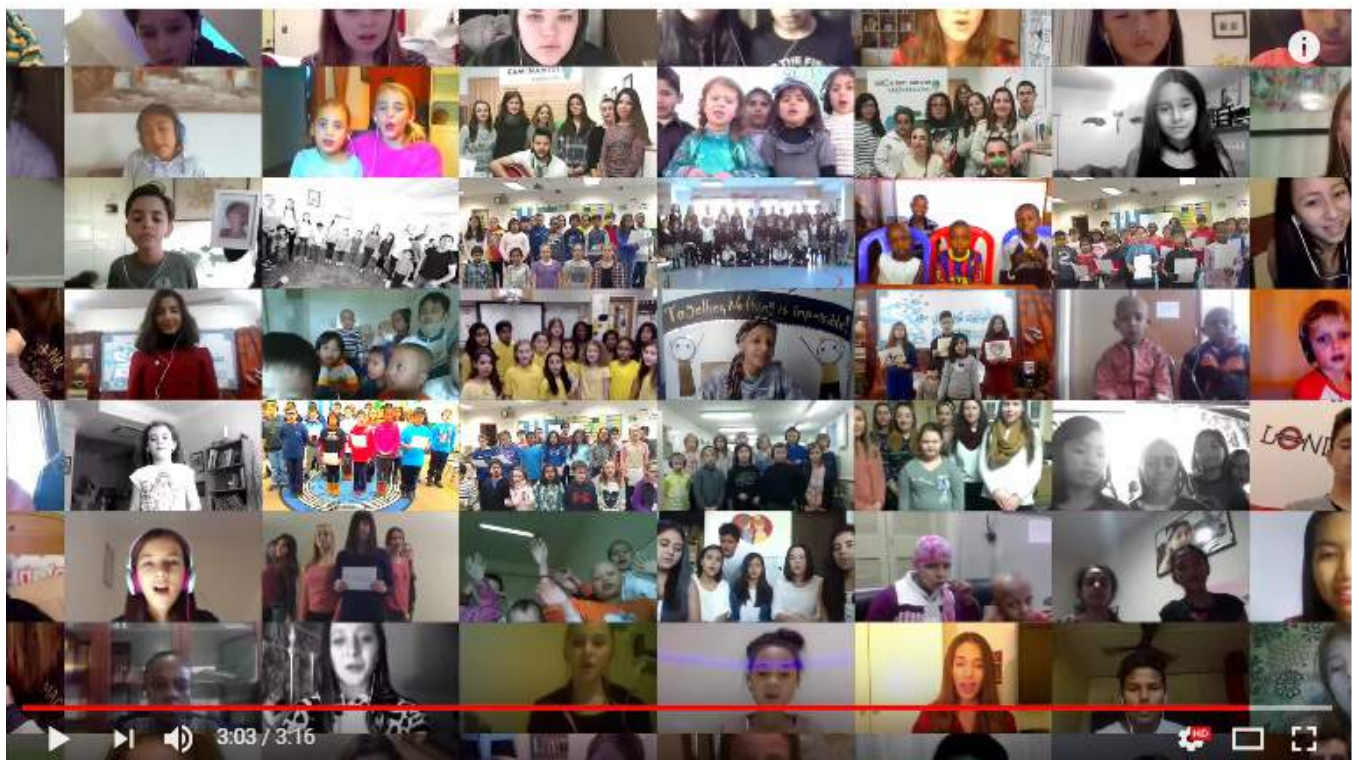
It went viral on the 3rd day of its launch, in many musical social media platforms. It has so far received 2 awards in 2 prestigious competitions: a Bronze Medal for the 2016 Cannes Gold Lion International Awards and a recognition as being among the Top 10 in the Best interactive Ads category.

The joint Global Premiere of the song "We Are One" and the 15th Celebration of International Childhood Cancer Day was held in Stockholm, Sweden on 15th February 2016. The groundbreaking and momentous occasion was graced by two Queens, both of whom are passionate about protecting and promoting the rights of children: Her Majesty Queen Silvia of Sweden and Her Highness Sheikha Jawaher Bint Mohammad Al Qasimi of the Kingdom of Sharjah in the United Arab Emirates. CCI Chair Carmen Auste and song co-writer Sophie Beck also were in the launch, to encourage children all over the world to continue showing their love and support for kids with cancer still courageously fighting for their lives. Ms. Auste invited all stakeholders to use the song to mobilize action and join forces in supporting children/adolescents with cancer, the survivors and their families. She underscored the message: We Are One: Together, Stronger.

The live streaming of the premiere was directed to an initial 55 countries. National media exposure in more than 100 countries over radio, television, print, and digital platforms as well as various community assemblies and special events in schools, universities, health facilities and hospitals, churches, work places and recreational areas, helped to further disseminate and popularize the song. It also brought visibility and media mileage to CCI member organizations who were able to leverage this for resource mobilization and volunteer build up.

CHANCE (Children Against Cancer), a CCI member in Lebanon, translated the We Are One song into Arabic and had popular

Lebanese celebrities, children and supporters take part in singing this local version. They report that it has been viewed on social media by more than one million viewers so far. In 2016, 75 CCI member countries participated in the campaign, along with an additional 55 countries reached through the support of members of the ICCD coalition (i.e UICC, SIOP, NCD CHILD, International Childrens



Child 4 Child - We Are One (Official video)

Palliative Care Network (ICPCN), International Association of Pediatricians (IAP), The MAX Foundation, St Baldricks Research Foundation and Children Living Among Neighbours (CLAN, Australia).

Since February 2016 onwards, it has been translated into 15 languages and dialects in the most populous regions and ethnic groups across the world. CCI members in various countries have worked tirelessly to promote this song and encourage everyone to make this not just the song of CCI members and community of supporters, but the song of the world for childhood cancer.

The song has now become a recognized anthem for childhood cancer, being used in forums, training events and conferences by CCI allies, collaborating partners and childhood cancer advocates/supporters. It continuously encourages and inspires diverse stakeholders to become "We Are One" in caring for and working together to rewrite the story of childhood cancer; create a story of hope and a better future for children/adolescents with cancer. The YouTube site and official video of the song is found in (Child 4 Child - We Are One (Official video).
<http://www.youtube.com/watch?v=PBzuYXCEDis>.

**This is not just a song..
this is a digital platform
that has helped to mobilize
support and galvanize action..**

**It is like a bridge that's been
created between the digital,
virtual world and the real world.**



When I was listening to the song, I was crying. I felt it described so well what I had gone through; what I was feeling and experiencing. I finally felt someone understood me.

Seeing all those kids singing, dancing, miming, made me feel I was special. This was for me a magical moment.. we were truly making history, bringing together all the kids of the world and helping to rewrite the story for kids like us.

- Teen Childhood Cancer Survivor -

We finally have our song ...we have a way to tell our story in music - the language of the heart and of the world and with other kids being involved, we feel that we are truly no longer alone

- Young Adult Childhood Cancer Survivor -

..the whole experience reminded us there are many good people out there who care ..are ready to be there for us, like those kids who sang, danced, mimed

- Tween (10-12 year old) Childhood Cancer Survivor -

I am always being asked about what i went through, how I felt... after hearing this song, I told my family and friends to just listen to this song I finally have an answer to their repeated question that I could not answer well before

- Tween (10-12 year old) Childhood Cancer Survivor -



3

SPOTLIGHTING CHILDHOOD CANCER: TURNING SEPTEMBER GOLD FOR KIDS WITH CANCER



GOLD IS THE COLOR OF CHILDHOOD CANCER; IT SYMBOLIZES HOW PRECIOUS AND PRICELESS CHILDREN ARE.

[#Gold4kidswcancer](#), [#Gold4Hope](#), [#Lightup4kidswcancer](#), [#Lightup4Hope](#), [#LightUpGold](#)

Traditionally, the countries that commemorate International Childhood Cancer Awareness Month in September are limited to developed countries like USA, Canada, Australia, Great Britain/United Kingdom, Ireland and Scotland.

In the 2014 International Conference in Canada, CCI members from across continents, agreed to own gold and promote the gold ribbon, especially during September, until it is recognized and seen as a symbol of childhood cancer, all over the world. CCI founding member, American Childhood Cancer Organization (ACCO), shared some of their best practices for gold ribbon promotion during Childhood Cancer Awareness Month.

It is said that Hope is the most powerful medicine; a key source of strength in conquering childhood cancer and the best gift



The Gold Ribbon Campaign is for the Heroes within our midst.

The children and adolescents who bravely and courageously fight cancer;

The survivors who beat cancer;

The families who fearlessly live with the realities of cancer and with the loss of a precious child;

The volunteers, staff and medical practitioners who passionately serve and dedicate their time to the childhood cancer community.



one can give to children/adolescents with cancer and their families. Hope that they will live to a brighter and healthier future; Hope that working together, we can stop avoidable deaths and unnecessary pain and suffering from childhood cancer.

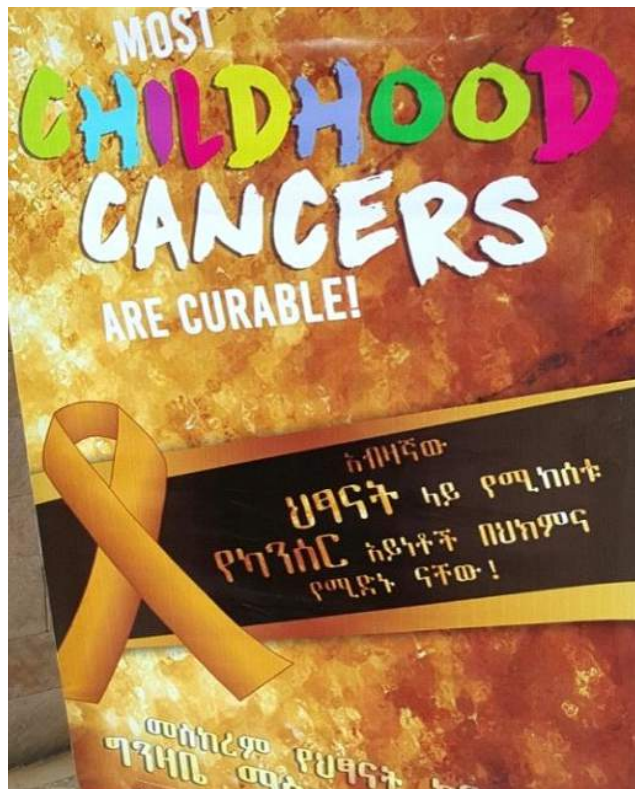
In 2015, Childhood Cancer International launched the Tribute Lighting Campaign, "Light Up Hope, Light Up Gold", which invited historic landmarks, iconic structures, monuments, bridges, natural environmental assets, to turn gold so as to show solidarity, caring and valuing for children/adolescents with cancer, survivors and their families.

In 2016, to further scale up the Light Up Hope, Light Up Gold Campaign, CCI highlighted THINK GOLD by promoting adoption of creative and innovative ways appropriate to their culture and context. This involved reaching out not only to iconic buildings, landmarks, natural monuments and popular places, asking them to Light Up or to display huge gold ribbons in their promenades and building facades but to also TURN SEPTEMBER GOLD, their own workplaces, homes, places of worship and community gathering places; to undertake golden events and special moments which will bring joy, smiles and hope to children/adolescents with cancer, survivors and their families. In Europe, the most sites lighted up gold or wrapped/marked by a gold ribbon, were reported in Spain, Ireland, Scotland, United Kingdom and Luxembourg. This was due to the passion, determination and creative initiatives of CCI member organizations in these countries. Noteworthy as well is that, Jet d'Eau, one of the tallest fountains in the world and the iconic symbol of Geneva's strength, ambition and vitality has been going gold every September for the last 3 years, through the initiative of CCI member Zoe Foundation.

In Spain, CCI founding member Federacion Española de Padres del Niños con Cancer (F.E.P.N.C.) introduced and promoted new ways to WEAR and DISPLAY the Gold Ribbon prominently.



In Ethiopia, Africa, CCI member, Mathiwos Wondu-Ye Ethiopia Cancer Society (MWECS), commemorated their first Golden September by displaying prominent banners and posters in the entrances of 3 of the most popular malls frequently visited by many people. In this way, they shared important key messages on childhood cancer as well as informed their communities that September is International Childhood Cancer Awareness Month. They also had an educational and entertainment activity for children with cancer and their families in the Black Lion Hospital which is the only cancer treatment center in Ethiopia.



In South Africa, CCI anchor member organization, CHOC Childhood Cancer Foundation and its celebrity Ambassador Phumeza Mdabe, South African singer, model, television presenter and actress, was extremely active with interviews and representation for the Go for Gold Africa Campaign. CHOC various offices in all the regions and localities had multiple, very well attended activities. Based on the audience figures of radio and TV stations, digital, online and print media, number of pupils at school assemblies, number of stakeholders in special events, CHOC estimates that they reached 9.96 million people, with number of individual exposures to CHOC and CHOC's message reaching up to 33 million. This of course include a considerable amount of duplication (in that a CHOC message was heard by the same person on more than one occasion) but nevertheless, given a population of 50 million, this is truly an exceptional media and public exposure for the Childhood Cancer Awareness Month in South Africa.

CHOC East London also did a wonderful version of the "We Are One" song which got many hits on YouTube and responses on facebook. The Early Warning Signs (EWS) DVD has also been used to raise awareness about the EWS of Childhood Cancer. In addition, a Thandi and Keemo puppet EWS video in Afrikaans and English has been released; the video involving CHOC and the Blue Bulls was uploaded to the Bulls Facebook book page, which has a reach of 216,624 followers. Video link: <https://www.youtube.com/watch?v=EHuVjAuZsro>



TAJ GOES GOLD
CHILDHOOD CANCER SURVIVOR LED CAMPAIGN
25 - 27 September, 2016



*The Taj Mahal listened & the Taj Mahal spoke!
Thank you Taj Mahal
from children with cancer and their families
from India and worldwide*

Pledge your Support here – www.cankidsindia.org

Together We Can Cancel Cancer
Issued by Kidscan Konknect Teenager & Young Adult Childhood Cancer Survivors.




In Asia, the most spectacular campaign was The Taj Goes Gold India campaign, spearheaded by CCI Anchor member organization CanKids and their Childhood Cancer Survivors (KidsKonnnect). This was launched during ICCD in over 55 cancer centres all over India. They advocated for the government to “Light Up Gold the Taj Mahal” with the challenge posed by CanKids chairperson Poonam Bagai, ... “when the Taj goes Gold this September, the world will know that India cares about children with cancer and their families.” As part of the campaign, child cancer patients all over India also participated in an “I deserve the best treatment, care and support” poster competition. This was by far the largest social mobilization campaign in India, engaging schools, colleges, universities, health and medical facilities and civil society, aiming to raise 300,000 pledges, one for each child diagnosed with cancer in the world. To date, 110,000 pledges have been reached.

The campaign, led by 8 survivors, adapted and localized the CCI material: 8 Reasons Why Children/Adolescents with Cancer deserve our support. It also had 8 demands: a clear national childhood cancer control plan and policy; additional dedicated pediatric oncology cancer centers; capable and more qualified manpower and health professionals; affordable, quality treatment focused interventions for specific childhood cancers that are highly curable like Hodgkins Lymphoma, Retinoblastoma (eye cancer) and Wilms Tumor (kidney cancer), acceptance of 18 as the age limit of childhood cancer, and increased family and civil society engagement. Campaign leaders and survivors also reiterated that access to best treatment care and support is our right, not just a privilege.

Pledges of support and affirmative action have come in from WHO country office in India, Ministry of Health Central Government, the Indian Academy of Pediatrics, and 2 state governments.

Since the Taj Mahal could not be lit up gold due to a Supreme Court ruling, the Archaeological Survey of India (ASI) agreed to an unprecedented 3 day ‘Taj Goes Gold for Childhood Cancer Exhibition’ within the monument’s premises from September 25-27. This was a first-of-its-kind exhibition on childhood cancer awareness. 1900 children with cancer and their families travelled from all over India for the occasion. Uttar Pradesh (UP) Chief Minister Akhilesh Yadav also extended his support to the campaign. Further, as a result of this advocacy, Uttar Pradesh Principal Secretary (Medical Education) Anup Pandey declared childhood cancer a health priority and along with the Principal Secretary (Health), promised to set up a task force for development of a childhood cancer control plan and policy.



Another innovative and memorable September Gold event in Asia was the human gold ribbon configured by volunteers of CCI member Anyo Foundation in Jakarta, Indonesia. This was undertaken together with children with cancer and their parents flying hundreds of gold yellow balloons bringing with it their ‘HOPE’ notes. Educational books on childhood cancer were also distributed to people at the venue and the surrounding areas. The event was well covered by local media and television.

4



WORKING TOGETHER TO CREATE BREAKTHROUGHS

1. ENGAGING IN COLLABORATIVE COUNTRY LEVEL WORK WITH WHO IN GHANA, ETHIOPIA, MYANMAR AND FIJI

As an essential step for country benchmarking and National Childhood Cancer Control Planning, a series of multi-stakeholder workshops was undertaken in 4 designated WHO NCD priority areas: Myanmar for Asia, Ghana and Ethiopia for Africa and Fiji in Oceania. The discussion and analytic framework used in the workshops was the WHO building blocks for childhood cancer care and control. Focus was on review of current state of childhood cancer care, barriers to access to care, challenges and strategies to improve survivorship, quality of care and the critical elements of the WHO childhood cancer care and control building blocks.

In Myanmar, the 2-day National Childhood Cancer Control Workshop was led by the Ministry of Health and Sports with support from WHO Country Office Myanmar, headed by Dr. Jorge M. Luna, WHO Representative for Country Office and WHO Headquarters representative, Dr. Cherian Varghese, Coordinator, Management of Noncommunicable Disease. St. Jude Children's Research Hospital was lead implementing agency and the primary donor for the activity, supported by World Child Cancer-UK.

The workshop technical resource team consisted of Dr. Carlos Rodriguez Galindo, Chair, Department of Global Pediatric Medicine and concurrent Director, International Outreach Program for St. Judes; Dr. Catherine Lam, Regional Director, Asia Pacific and St. Judes Department of Global Pediatric Medicine, Dr. Ramandeep Arora (SIOP and SIOP PODC representative), Dr. Robert Carr (Consultant Haematologist for Guy's St Thomas' NHS Foundation Trust in London) and Carmen Auste, CCI Global Chair. Poonam Bagai, CCI Board Treasurer and Capacity Development Portfolio Manager and Hanife MacGamwell, Nurse Trainer and Instructor, CanKids, India were also on hand to participate and contribute to the workshop discussions.

The two local participating health facilities were Yangon Children's Medical Center and Mandalay Children's Hospital. Stakeholders included public sector leaders, health professionals, academicians from higher educational and training institutions, leaders/officers of local professional societies (i.e. Myanmar Society of Oncology; Myanmar Society of Hematology; Myanmar Medical Association; Myanmar Nurses Association) and civil society organization (i.e. Myanmar Blood Donor Association, Love and Hope Foundation, Richardson Center for Global Engagement, Golden Rose "Shweyaung Hninzi Cancer Foundation).

Among the agreed follow through commitments that CCI made



to WHO re follow up local action in Myanmar are support for: a) family and caregiver engagement, consistent with WHO Integrated, people-centred health services through Organization of Golden Hands Family Group in Yangon Children's Medical Center and Organization of core parents team for Mandalay Childhood Cancer Hospital; b) training and ongoing coaching of one Medical Staff from Yangon Children's Medical Center, Myanmar in case management, counselling, play therapy and psychosocial support; c) Capacity building of parent leaders in the family group; d) engaging a Family Support Services Coordinator (1 for each facility) to help reduce abandonment, improve patient and family experience, lessen burden and distress of families; e) development of parents/ family guide for distribution to families and caregivers of newly diagnosed kids with cancer, incorporating WHO messages on patient safety, pain management, nutrition and integrated people-centered health services; f) Capacity development support for 2 day training and logistical support of 50 nurses from Yangon Children's Medical Center, 7 satellite centers and Mandalay Childhood Cancer Hospital (scheduled implementation December, 2017).

In Ethiopia, the 2-day in country workshop was held in Jimma, led by the Federal Ministry of Health and WHO. CCI supported WHO and collaborated with SIOP and The ASLAN Project in the organization, planning and follow-up of the workshop. The workshop theme was Children with Cancer in Ethiopia: Improving Access, Survival and Quality of Care. There was support and personal participation from The First Lady of Ethiopia, Her Excellency, Mrs. Roman Tesfaye, who also heads the National Cancer Control Committee. It was agreed with WHO that CCI through its local members



reach, impact and media mileage; c) Reduce abandonment and improve survivorship based on targets and indicators agreed upon in the workshop; and c) Build a family lodge. CCI member GHAPACC intends to hold the ground breaking ceremonies for the Parents/Family Lodge and Multi-purpose Center, in 2017. They will seek support from the First Lady Mrs. Rebecca Akufo-Addo. A 2-day Pacific Regional Childhood Cancer Conference was convened by the Fiji Health Ministry and the WHO South Pacific Advisor for NCDs. World Child Cancer Charitable Trust, New Zealand, CCI collaborating partner for Oceania, CCI Oceania and SIOP Oceania supported WHO in the organization, planning and follow-up of the workshop. Around 80 medical practitioners, nurses, parents and key stakeholders from 12 Pacific countries participated in this meeting in which updates were presented and the new Pacific Regional Child Cancer Portal and Registry was launched. Among the workshop agreements were that CCI Oceania in collaboration with World Child Cancer Charitable Trust New Zealand, SIOP Oceania and New Zealand National Children's Cancer Network (NCCN) would conduct the following activities in collaboration with WHO: a) Twinning visits of doctors and nurses from New Zealand and Australia to Fiji, in collaboration with Ministry of Health of Fiji, CCI and SIOP Oceania; b) Support to Ministry of Health Fiji for employment of an outreach nurse and purchase of a vehicle for patient visits and follow up care.

would conduct follow through activities in collaboration with WHO: a) Awareness raising campaign on childhood cancer signs and symptoms during International Childhood Cancer Awareness Month (ICCAM; September) and International Childhood Cancer Day (ICCD; February) using existing WHO guidance on early diagnosis of childhood cancers; b) Conduct of Consultative Workshop on Childhood Cancer Care Standards and c) Formation of Technical Working Group on Childhood Cancer that will develop Guidelines for Treatment and Care of Children/Adolescents with Cancer. To assist and facilitate commitments to improve nutritional status, survivorship care and quality of patient and family experience, financial support will be provided by CCI through American Childhood Cancer Organization, to cover nutritional support of kids with cancer under treatment in New Cancer Treatment Centre and assistance for meals for their parents.

In Ghana, CCI in collaboration with SIOP AFRICA (headed by Professor Dr. Lorna Awo Renner) and supported by World Child Cancer UK (represented by CEO Jon Rossner), assisted WHO (represented by Country Head Dr Rosaline Doe) and the Ghanaian Ministry of Health, in the organization, planning and follow-up of the country assessment workshop. It was agreed that CCI through its member GHAPACC (Ghana Parents Association for Childhood Cancer), would conduct the following activities in collaboration with WHO, Ministry of Health, SIOP Africa and WCC: a) Increase awareness on childhood cancer myths and facts including celebration of International Childhood Cancer Day and International Childhood Cancer Awareness Month; b) adapt a health system approach such that Ghana Health Service (GHS) staff and Community health officers who go on outreaches can be engaged and mobilized. Chiefs, opinion leaders, assembly members, traditional and spiritual leaders and media should also be engaged to optimize



2. MAKING OUR VOICES COUNT IN CREATING AN EVIDENCE BASED CASE FOR INVESTING IN CHILDHOOD CANCER IN LMICS

The Lancet Oncology Commission on Sustainable Paediatric Cancer Care was formed to undertake a comprehensive analysis leading to the development of an investment framework and evidence based case for investing in effective interventions to address childhood cancer. The Commission Leaders are: Dr. Rifat Atun, Professor of Global Health Systems and Director of the Health Systems Cluster at Harvard University. Dr. Carlos Rodriguez-Galindo, International Outreach Program Director and Executive Vice President of St. Jude Childrens Research Hospital and Chair of the Department of Global Pediatric Medicine, Dr. A Lindsay Frazier, Associate Professor of Pediatrics at Harvard Medical School and Associate Professor of Epidemiology at Harvard T H Chan School of Public Health and Dr. Sumit Gupta, Staff Oncologist and Clinician Investigator at the Hospital for Sick Children, Assistant Professor at both the Faculty of Medicine and the Institute for Health Policy, Management and Evaluation at the University of Toronto.

The voice of parents and families of children/adolescents with cancer in this prestigious Lancet Oncology Commission on Sustainable Pediatric Cancer Care is Ruth Hoffman, Vice Chair/incoming President Elect of Childhood Cancer International and Executive Director of American Childhood Cancer Organization. The Commission intends to: a) establish a set of pediatric cancer goals to be reached by 2030, b) estimate the benefits (in terms of deaths avoided and economic benefits) that would be realized by achieving these goals and c) estimate what the costs would be and what care path should be followed to achieve these goals.

Three working groups have been formed. Working Group 1 seeks to determine the current burden of disease for pediatric cancer in LMIC, as well as the projected burden for 2030 if no action is taken to reduce it. Working Group 2 of which Ruth Hoffman is a member, assesses the number of services available for pediatric cancer and the levels of services that are available. Finally, Working Group 3 seeks to determine the cost of pediatric cancer treatment in LMIC. Findings and recommendations of these working groups will be presented to the World Health Organization (WHO) during the World Health Assembly of May 2018. Ruth also serves as a commissioner on the Pediatric Blue Ribbon Report of the Lancet Oncology Commission Report for U.S. Cancer Moonshot Initiative. Its title is Future Cancer Research Priorities in the USA: a Lancet Oncology Commission.



Three other members of the CCI Board have also been selected to participate in the Lancet Commission Expert Panel Study for Sustainable Pediatric Cancer Care. This Delphi study (a consensus-building systematic exercise) aims to support health systems mapping and the development of an investment case for childhood cancer.

3. LEVERAGING TECHNOLOGY FOR LASTING SOCIAL IMPACT: STRATEGIC ALLIANCE BETWEEN CCI, NET SUITE AND ORACLE

CCI collaborated with NetSuite.org which aims to leverage its technology to help charities achieve a lasting social impact. The Strategic Alliance involves a donation in kind of a web platform and software as well as free coaching and technical support services for eligible CCI members. It is envisioned to help CCI community of members to gain access to free NetSuite software and thus, accelerate achievement of its goals and mission. Carmen Auste, CCI Chair, initiated this strategic alliance with Net Suite and Oracle teams.

Through the Light CMS donation, NetSuite.org aims to empower CCI members by providing them with a free online content management platform that translates the voice of each member organization into web pages of impact storytelling. This lifetime donation provides a viable website that enables CCI member organizations to achieve their organizational goals especially those related to stakeholder engagement, social mobilization and networking, fundraising and resource mobilization and program development. The grant for each approved CCI member organization covers free web hosting, easy access to content and e-mail support service.

4. FACING THE CHALLENGE OF RARE CHILDHOOD CANCERS IN THE EUROPEAN UNION

The public health challenge posed by rare cancers combines both the typical problems of rare diseases (such as the limited professional expertise available in the community, or the difficulties in clinical research) and those of cancer, with the need of a timely and appropriate diagnosis and optimal treatment from the very beginning of the patient's journey. An accurate clinical, pathologic and biological assessment of the disease of the individual patient is key to survival and cure, as well as expert clinical decision provided by a multidisciplinary team.

The Joint Action on Rare Cancers (JARC) is a health policy project which aims to integrate and maximize efforts of the European Union (EU) Commission, EU Member States and all stakeholders to advance quality of care and research on rare cancers, for the next 3 years (October 2016 – October 2019). The Joint Action on Rare Cancers is a multi-stakeholder collaboration between 18 Member States and the European Commission, coordinated by the Fondazione IRCCS Istituto Nazionale dei Tumori di Milan. There are 35 partners involved in the JARC including 8 Ministries of Health/Cancer Control Programme representatives (Cyprus, Czech Republic, France, Ireland, Italy, Malta, Poland, and Spain) and 27 universities, public health institutions, cancer registries, oncological institutes, patients' associations (CCI members) and other societies/organizations (Organization of European Cancer Institutes – OECI, The European Society for Paediatric Oncology - SIOPE). The kick-off for this initiative took place in the beginning of November 2016.

CCI Europe and SIOPE see their involvement in JARC as an opportunity to influence national cancer plans to prioritize all childhood cancers in the agenda of the EU and the member states as well as contribute to facilitating harmonization of practices and funding of research.

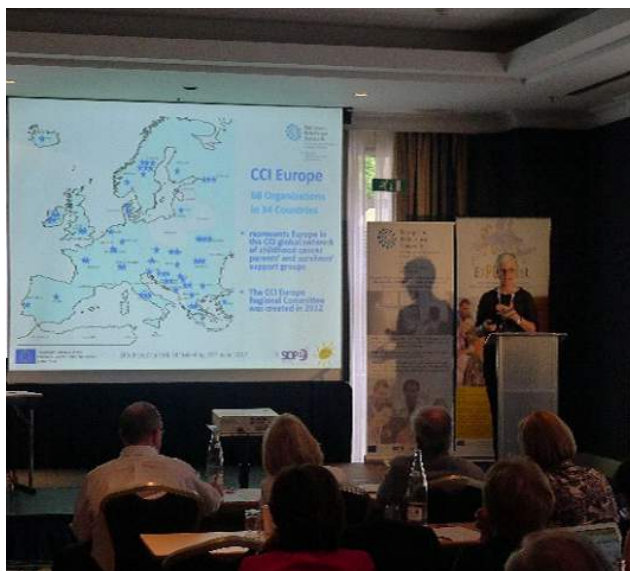
Since proper referral of patients and effective clinical networking are crucial in rare cancers, JARC decided to shape its efforts, in essence, around the new European Reference Networks (ERNs). Three of these are specifically devoted to rare cancers (ERN PaedCan, ERN EURACAN (focus on solid tumours), ERN GENTURIS (genetic tumour risk syndromes) and have been conceived by the EU Commission as a means to provide highly specialized healthcare for rare or low-prevalence complex diseases.

The work package on childhood cancers, which is spearheaded by SIOPE and includes CCI as collaborating partner, focuses on a) making recommendations on accessibility of essential treatments across Europe, b) access to innovative therapies through referrals to clinical trials across Europe, c) models of healthcare for survivors of childhood cancers based on prior projects, and d) identification of solutions for optimal care and research for young people with extremely rare cancers. For further information, visit: <http://jointactionrarecancers.eu/>

5. REDUCING INEQUITIES IN CHILDHOOD CANCER SURVIVORSHIP AND HEALTH CARE SYSTEMS CAPABILITIES ACROSS EUROPE

European Reference Networks (ERN) create a clear governance structure for knowledge sharing and care coordination across the EU to improve access to diagnosis and treatment, as well as the provision of high-quality healthcare for patients. They will facilitate the sharing of knowledge, experience, medical research, teaching, training and resources. They are networks of centers of expertise and healthcare providers as well as patients and parents organizations that are organized across borders. ERN are part of the legal framework of the EU Directive on Patients' Rights in Cross-Border Healthcare Directive adopted in 2011.

The forerunner project ExPO-r-Net (European Expert Paediatric Oncology Reference Network for Diagnostics and Treatment; 2014-2017) was created in order to reduce current inequities in childhood cancer survival and health care capabilities among EU member states. It was aimed at creating mechanisms to support cooperation on cross border healthcare and in the innovative delivery of health care. CCI was a partner in this project via the Austrian Childhood Can-



cer Organization. One important task where CCI Europe was involved was on-site visits to several EU countries, as well as to non EU countries. Parents and patient representatives from CCI joined doctors who were partners within ExPO-r-Net. The clinical centers visited was suggested by the respective National Paediatric Haemato-Oncology Societies. The aim was to determine on which level the center should start within the European Reference Network for Paediatric Cancer (ERN PaedCan) (e.g. "Hubs of coordination"; affiliated center or in the framework of a twinning program (to support countries with a low health expenditure annual rate). The (CCI) representatives had an additional objective during these visits; to foster and build the relationship with the local Parents and Patients organizations and provide support, if needed and desired.

ERN PaedCan aims to provide paramount requirements for Cross-border healthcare (CBHC). Given the potential burden on families seeking cross border health care, i.e. leaving their cultural and language environment and entering social isolation for treatments that may extend over months, ERN PaedCan intends to establish mechanisms to facilitate movement of information, guidelines and knowledge via cross-border virtual tumor boards and virtual consultation systems. High-quality, accessible and cost-effective healthcare for childhood cancer is achieved by strengthening the integration of pre-existing knowledge and expertise, and fostering stronger cooperation between patients/parents/survivors, professionals and healthcare authorities.

CCI Europe is building a sub-network, which meets the needs of the ERN PaedCan. It will be the link between the coordinator of the ERN PaedCan and the national contact points - Patients and Parents groups in Europe.

A key role of CCI Europe will be to keep the community up to date and disseminate all important information about innovations and/or reforms in the ERN. CCI Europe will provide the coordinator with feedback concerning the ERN, which will be given by the national contact points. CCI Europe will also continue its advocacy activities within the ERN and will try to represent the Patients and Parents voice as effectively as possible.

6. BUILDING AWARENESS ON EARLY WARNING SIGNS AND SYMPTOMS OF CANCER FOR MORE TIMELY AND RESPONSIVE ACTION

6.1 The Early Warning Signs and Symptoms (EWS) campaign was launched on International Childhood Cancer Day (ICCD) 2014 by the Union for International Cancer Control (UICC), Childhood Cancer International (CCI and the International Society of Paediatric Oncology (SIOP). The goal of the campaign was to increase knowledge and awareness of childhood cancer signs and symptoms, especially among health workers and encourage prompt referrals to appropriate health facilities for timely testing, diagnosis and treatment. The campaign was designed as a three-year project with different materials produced each year so as to develop a suite of learning, training and coaching activities. The kick off campaign materials included a poster and pocket card, using icons/visuals to spotlight key early warning signs of common childhood cancers and common differential diagnoses. CCI translated the posters into 70 local languages and dialects which were then adapted for use in different countries and settings. In the second year (2015), to deepen understanding and recognition of early warning signs for 6 of the most common types of childhood cancer, the campaign released talking head videos. These were narrated by doctors, a nurse, a cancer survivor (CCI member) and a parent (CCI member)



to contribute to increased early diagnosis by primary healthcare professionals or timely referrals by community volunteer health workers.

In 2016, the final year of the campaign, CCI worked with UICC in developing strategies and tools to facilitate harvesting and consolidation of learnings and insights from the campaign. A webinar series from different countries and regions that had extensively used and promoted the materials was launched. The initial webinar involved 3 CCI members as resource (YKAKI,



Indonesia; Fundacion Nuestros Hijos, Chile and Bless the Child Foundation) An evaluation survey tool was developed in 3 languages (English, French, and Spanish) and sent out to CCI, UICC and SIOP members. A learning material compiling all these into one resource-book for easy referral will be developed. This will include the posters, pocket cards, talking head videos scripts, presentations, and recorded webinars. It is expected to be available by last quarter 2017.

6.2 Developing a Capacity Building Initiative on Raising Community Awareness on Early Warning Signs of Childhood Cancer; Designing an exploratory study on Community Knowledge Attitude Practise (KAP) on Childhood Cancer

CCI Asia through its member YKAKI - Indonesia, headed by Ira Soelistyo, has collaborated with the Universitas MH Thamrin – Jakarta to undertake these initiatives in 4 strategic and highly populated areas of Indonesia (Bekasi, Depok, North and East Jakarta) starting early 2017. This pilot project intends to establish a good practice model that can be localized and adapted in other low resource countries with similar cultural context, challenges and settings. The project will be completed in the last quarter of 2018.



7. SCALING UP PALLIATIVE CARE AND PAIN MANAGEMENT INITIATIVES

7.1 Asia - China. Enhancing Capacities on Pain Care Management and Palliative Care

The roots of this first CCI-Asia and SIOP-Asia Capacity Building Collaboration can be traced back to the 2013 SIOP- CCI Annual Conference in Hong Kong. Childhood Cancer International member organization, Pau Kwong Wun Charitable Foundation (PKWCF) of Hong Kong, under the leadership of Benson Pau, its Founder and Chairman, spearheaded the campaign "Every Child with Cancer Deserves a Chance". All funds raised from this campaign were designated for capacity building projects of CCI-Asia. Mr. Pau is CCI Asia Regional Head and a previous CCI Chair and Vice Chair.

The 3 (three) sub-goals for this collaborative project are:

a) Improve all medical staff understanding, ability to assess and effectively handle pain management of children with hematology & oncology diseases in Hematology & Oncology Center of Beijing Children's Hospital, China (BJCH); b) Improve understanding, ability

to assess and assist in effective pain management among parents and children with hematology and oncology diseases in the Center; c) Improve the atmosphere and environment in the Center to help relieve children's pain and minimize distress during stay in hospital. The support of Dr. Zhou Xuan, project leader of BJCH, Dr. Ma Xiaoli and Professor Zheng Huyong of BJCH, Professor Chi Kong Li, SIOP Asia Head, together with Ms. Jeanny Cheung and Ms. Cheng Kei, was invaluable in the training of doctors, nurses and palliative care team members.

To maximize the learning opportunity, training participants did not only come from BJCH but included medical staff from 4 other nearby cities: Shanghai, Shandong, Guangzhou and Zhengzhou. Participants were very much encouraged and inspired by the training. Many practical problems were also worked out and resolved during these trainings and workshops. The practical training for lead nurses was undertaken in collaboration with the Prince of Wales Hospital in Hongkong and the support of SIOP Asia President, Dr. Chi Kong Li.

7.2 Latin America – Chile

Fundacion Nuestros Hijos with support from OPS is implementing a Palliative Care and Pain Relief Program (PCP) for medical staff and parents working with children with cancer in four LATAM countries: Bolivia, Colombia, Paraguay and Peru. The program will: give theoretical and practical tools to physicians, nurses, multidisciplinary oncology teams, parents; contribute to the creation of public policy addressing this issue as well as decrease the burden on families of children with cancer. As a first step, 11 professionals from 6 oncology units from these countries were invited to participate in a Training Program on Palliative Care and Pain Management in Children with Cancer.



8. CREATING BREAKTHROUGHS THROUGH EDUCATIONAL AND LEARNING ALLIANCE

The shared mission of the European Society for Blood and Marrow Transplant Nurse Group (EBMT NG) and Nurses No Frontiers Association (NNF) is sharing knowledge and hematology -oncology experiences world wide as well as conducting on-site training courses in low and middle income countries. On the other hand, CCI believes that its mission of helping ensure that children with cancer everywhere get the best possible treatment and care, can be actualized with the presence of caring, capable and competent nurses and medical staff. Thus, an educational and learning alliance was formed with EBMT Nurses Group, NNF and CCI, under



the leadership of Aleksandra Babic, EBMT NG President and Founder of Nurses No Frontiers, Carmen Auste, CCI Global Chair and Benson Pau, CCI Asia Regional Head. The formation of this alliance was spearheaded by Luisa Basset, CCI Board Secretary and member of the CCI Europe Regional Committee and Eugenia Trigo, EBMT NG Pediatric Committee Chair, who are both based in Spain.

Guangzhou, China was selected as the first training location as there were 10 hospitals with pediatric oncology wards in Guangzhou, with 3 of them having BMT departments. More importantly, Guangzhou also had a CCI member organization, Guangzhou Gold-ribbon Special Children Parents Center (GGSCPC), working with and serving all these 10 local medical centers. The Parents group (Guangzhou Gold-ribbon Special Children Parents Center) took charge of the preparation and dissemination of communication mate-

rials, promotion of the training, liaison with local supporting institutions as well as managed and provided the administrative requirements of the training. The Pau Kung Won Charitable Foundation of Hongkong (another CCI member) served as liaison to the EBMT/NNF nurses team and took charge of all logistical requirements. They also provided technical guidance and support to the Guangzhou training team.

The training was held on 26 – 27 February, 2016 in the Second Affiliated Hospital of the Sun Yat Sen University in Guangzhou. This was made possible by the support of Professor Fang Jianpei who provided the training venue at no charge. The choice of venue was also auspicious as the very first training school and program for nurses in China was in Sun Yat Sen University. There were 5 speakers from the EBMT and NNF Nurses Group, coming from 4 different European countries: Aleksandra Babic - President of EBMT NG (Switzerland), Eugenia Trigo - Pediatric Nurse Committee Chair (Spain), Merja Stevanli - EBMT NG Board (Denmark), Sara Zulu - Secretary of the EBMT NG Board (UK), and Julia Ruiz - Member of the EBMT - Spanish Nurses Group. More than 150 nurses from the Guangzhou hospitals and 10 hospitals from 9 other provinces of China, attended the training course. The training was a great learning experience for everyone. It received excellent feedback from all participants and local supporting partners as it provided updated, practical information on good practices and processes. Attendees repeatedly said they learned a lot and it was a very interesting and enlightening forum. The plenary discussions/open forum was very rich and in depth, with many practical issues being explored with thanks to the assistance of interpreters who were medical staff of the hospital teams from Second Affiliated Hospital, Sun Yat-Sen University and Nanfang Hospital.

In December, 2016, NNF and EBMT Nurses Working Group travelled to Mumbai, India to conduct a 2 day training course for Nurses. The local collaborating hospital was the Advanced Centre for Treatment, Research and Education in Cancer (ACTREC) at the Tata Memorial Center while the CCI member local host was Can Kids India. The Training programme was co-designed with the Nurses Department of ACTREC and had 205 participants from different hospital in different parts of India.

The training resource team was composed of Aleksandra Babic, EBMT Nurses Group President and NNF Founder, Michelle Kenyon and John Murray (UK), Eugenia Trigo (Spain), Alberno Castagna (Italy) and Merja Stevanli. Topics focused on practices for nurses care of BMT



patients, Infection Control, Supportive Care and Symptoms Control., Quality of Life after BMT, Palliative Care and Nursing Management of various BMT related complications and conditions were likewise discussed. Feedback from participants indicated that analysis of workshop events was very highly rated especially in relation to relevance of workshop topic, being interesting and highly useful in day to day practice and innovativeness of teaching methodologies. The 3rd Nurses Training is scheduled on December, 2017 in Yangon, Myanmar.

9. CREATING AN ENABLING AND SUPPORTIVE ENVIRONMENT THROUGH ADVOCACY ALLIANCES AND COALITIONS

9.1 CCI as among the Global Partners of the Universal Health Care Coalition

In 2015, Universal Health Coverage was endorsed by the United Nations General Assembly as one of the Sustainable Development Goals for 2030. That same year, the Rockefeller Foundation spearheaded the launch of the Universal Health Care Coalition and the celebration of Universal Health Care Day every 12th of December. Dr. Margaret Chan, previous Director-General of the World Health Organization said "I've said it before and I'll say it again: universal health coverage is the most powerful concept that public health has to offer. Ensuring access to health without financial hardship builds fair, stable and cohesive societies." Since ensuring better access to affordable, safe and quality care is an integral part of the CCI mission and goals, CCI joined the coalition.

On Universal Health Coverage Day 2016, partners recognized primary healthcare as a key priority on the pathway to achieving health for all. Researches have found that a strong primary health care system and community based mechanisms is essential to improved and increased survivorship from cancer. It can facilitate increased awareness, early diagnosis, proper referral and follow up care as well as serve as a platform for community based palliative care and pain management.



Strong primary health care improves, protects and saves lives, especially in the poorest and most marginalized communities, said Dr. Chris Elias, President of the Global Development Program at the Bill & Melinda Gates Foundation. "If the global community is serious about reaching universal health coverage, we cannot afford to ignore the pressing need for better investments in primary health care systems".

Annually, the coalition offers competitive grants to members of the coalition who will undertake high impact local activities for UHC on December 12. CCI members are eligible recipients of this grant.

9.2 USA: STARS ACT

The American Childhood Cancer Organization (ACCO) is a founding member of the Alliance for Childhood Cancer, USA. Working together with nationally based childhood cancer organizations and the entire childhood cancer community it sought to pass the Childhood Cancer STAR (Survivorship, Treatment, Access and Research) Act.

In December 2016, the US House of Representatives passed the Childhood Cancer STAR Act—the most comprehensive childhood cancer bill ever taken up by the US Congress.

Sadly, this bill did not pass the Senate prior to the end of the year. With the start of a new White House Administration in January 2017, it meant that the STAR Act needed to be reintroduced in both the House and Senate, with co-sponsors signing on to the bill again. ACCO continues to work with Senators Capito and Alexander as well as our House Champion Congressman McCaul to see this important legislation passed into law.

9.3 ASIA - Philippines: National Integrated Cancer Control Act (NICCA)

Cancer Warriors Foundation is a founding member of the Cancer Coalition Philippines which seeks to pass into law a National Integrated Cancer Control Act (NICCA). Other founding members are Philippine Cancer Society, I Can Serve (breast cancer), Brave Kids (Childhood Cancer), Carewell Foundation, Philippine Children's Medical Center and PHAP CARES. The Coalition envisions one law covering all cancers, of all ages and gender, spanning critical needs and priority reforms in the whole cancer care continuum. It imagines a tiered network of cancer ready health facilities in all levels, providing accessible, affordable and optimum quality care for all cancer patients. The coalition is using the WHO building blocks for cancer control as the framework for the development of the bill as well as the proposed World Health Assembly resolution of the World Health Organization. It has started to reach out to legislative champions, leaders of various cancer focused professional societies, civil society organizations as well as celebrities whose lives and families have been touched by cancer.

9.4 Europe - Unite2Cure: is a network of parents, parent organisations and patient advocates from across Europe, which is calling for better treatment and better access to treatment for children and young people with cancer. CCI Europe has established a partnership with Unite2Cure since April 2016, in regards to collaborating on research and regulatory topics.

This network is supported by many doctors, paediatric oncologists and researchers from all over Europe.



On the occasion of the European Commission evaluation of the Paediatric Medicines Regulation and report due in 2017, the pan-European childhood cancer and broader community are calling on the European Institutions to support the urgent revision of the Paediatric Medicines Regulation in line with these mutually agreed multi-stakeholder recommendations:

1. Ensure that the obligation to undertake a Paediatric Investigation

Plan is based on how a drug works and its capacity to address an unmet medical need in children - rather than the type of disease in adults for which it is first introduced.

2. Set up a mechanism to choose the best potential drugs and prioritise, among drugs developed by different companies, in relation to the real needs of children affected by rare cancers.

3. Reduce delays in paediatric medicines reaching children

In December 2016, in response to this advocacy, the EU Parliament approved a resolution proposing revisions on the 2007 regulations so as to accelerate development of safe and effective innovative therapies for children/adolescents with cancer.

10. SUPPORTING AND/OR ENDORSING RESEARCH TO PROVIDE ROBUST EVIDENCE BASE FOR ADVOCACY, POLICY AND PROGRAM DEVELOPMENT

10.1 Advancing Childhood Cancer Care and Cure in Latin America

Fundacion Nuestros Hijos (FNH; Chile) undertook together with Childhood Cancer International, Union for International Cancer Control (UICC), Sick Kids Hospital, Unit for Policy and Economic Research in Childhood Cancer (PERCC), a collaborative 17 country project entitled "Advancing the Development of National Childhood Cancer Control Plans in Latin America". In order to ensure alignment of efforts with regional development institutions and to facilitate the involvement of national health authorities, the Pan American Health Organization (PAHO/WHO) was engaged as a formal partner in the project.



The final list of the 17 participating LATAM countries include: Chile, Argentina, Brazil, Paraguay, Uruguay, Peru, Colombia, Bolivia, Ecuador, Guatemala, El Salvador, Panama, Honduras, Costa Rica, Mexico and Cuba. For Dominican Republic, information was available only at the civil society organizational level.

The principal objective of the project was the generation of detailed health systems evidence on how childhood cancer is currently organized, governed and financed, with a view to developing evidence-informed public policy recommendations to improve childhood cancer care in the region. It also intends to showcase successful models in Latin America where childhood cancer is effectively integrated across health service delivery platforms, including varied child health platforms, programs and initiatives, and, where lacking, to explore challenges to such integration. Finally it aims to engage leading child health organizations at national,

regional and global levels to provide greater attention to childhood cancer surveillance and management as an integral part of child health. The research report is expected by mid 2017.

10.2 Capturing Trends and Disparities in Survival of Children with Leukemia, Brain Tumours and Lymphoma

CONCORD is the largest international collaboration on survival from cancer. The CONCORD programme is currently endorsed by many influential organisations, including UICC, SIOF and the European Cancer Patient Coalition. Childhood Cancer International, was invited by Concord to endorse them since they considered CCI has an important group of parents of children with cancer, involved in advocacy and health policy worldwide.

The CONCORD programme established world-wide surveillance of trends and disparities in survival for several types of cancer, using population-based cancer registry data. CONCORD-2 was the first study to estimate worldwide cancer survival trends for children diagnosed with ALL, involving some 75,000 children diagnosed between 1995 and 2009.. It has been used to drive cancer strategy in England and several other countries, and the new global campaign on inequalities in access to cancer care and survival launched by the International Atomic Energy Agency's Programme of Action for Cancer Therapy. Visit their website for more information: <http://csg.lshtm.ac.uk/research/themes/concord-programme/>

In 2016, CONCORD-3 was launched. It will be based on data for patients diagnosed as recently as 2014. In addition it will be collecting data on children with leukaemia, and will also analyse lymphomas and brain tumours for the first time.

10.3 Switzerland - Sports Therapy Program for Kids with Cancer

A ground-breaking research program which began in Canada has been continued in Switzerland, funded in its entirety by CCI member Zoe4Life . Sports Therapy for children being treated for cancer has demonstrated improvements in physical ability, sleep pattern and self-esteem during a three month study in Canada. The Swiss study, which ran for a year, was done by Zoe in collaboration with the University of Lausanne Sports and Health Center (UNIL) and the Lausanne University Hospital (CHUV).

10.4 Canada - CCI endorsed the study "Mental health outcomes in childhood cancer survivors, sibling and mothers" by Dr. Sumit Gupta of Sick Kids Canada. It was a 3 year longitudinal study funded by the Canadian Cancer Society Research Institute. Initial findings will be presented at the 2017 American Society of Clinical Oncology and will help in program design for psychosocial support to siblings and family, especially the mother.

11. COLLABORATING TO BRING SMILES, JOY AND HOPE TO CHILDREN/ADOLESCENTS WITH CANCER AND THEIR FAMILIES IN EASTERN EUROPE AND AFRICA

Childhood Cancer International Europe collaborated with International Atomic Energy Agency Programme of Action for Cancer Therapy (PACT) IDepartment of Technical Cooperation by linking them up with 2 CCI member organizations: 1 in Eastern Europe (Hearts for Kids with Cancer) and 1 in Africa (KIDZCAN, Zimbabwe).

Hearts for Kids with Cancer was in the process of building their first

parent house in Bosnia and Herzegovina, Sarajevo and received some assistance for this. KIDZCAN, Zimbabwe, received assistance for materials they needed in order to provide psychosocial support to children/adolescents with cancer as well as to safely transport medicines and vaccines.

BRING SMILES, JOY AND HOPE!



4



BUILDING AND ENHANCING CAPACITIES

2016 Regional Meetings, Conferences, Publications and Learning Materials.

As part of its commitment to continuous enhancement of member's capacities, CCI sponsors annual regional meetings and conferences across 5 continents (Asia, Latin America, Europe, Africa, and Oceania).

CCI-Africa and CCI-Latin America holds its regional conference every two years while CCI Asia and CCI Europe has an annual event.

2016 saw a noticeable increase in the number of participants and/or countries attending the regional meetings/conferences in Asia and Europe as well as enhanced interest from non-CCI members to attend these events.

In addition to these CCI sponsored learning and networking activities, CCI member organizations also sponsor their own local/national/international meetings, conferences, multi-stakeholder and sectoral forums and dialogues. The list of this can be found in the CCI website.

PROMOTING AND WORKING TOGETHER TO IMPLEMENT EUROPEAN STANDARDS OF CARE FOR CHILDREN WITH CANCER

The 7th CCI Europe Regional Conference was focused on European Standards of Care which is the recognized reference document describing the requirements for centers specialized in the treatment of children with cancer in Europe, so that all children in Europe will receive the same standard of care, no matter where they live. This conference took place from April 22nd to 24th 2016 in Belgrade (Serbia) – with more than 100 participants from nearly 30 European countries.

The conference was organized by the CCI Europe Regional Committee in collaboration with the Serbian Childhood Cancer Network.

It was hosted by Irina Ban & Vladimir Radulovic of the Serbian Childhood Cancer Network. Also in attendance as special guests were, His Excellency Mr. Michael Davenport from the European Union and Zlatibor Lončar, from the Ministry of Health in Serbia.

The meeting provided an opportunity for the participants to have a more extensive and deeper understanding on what CCI Europe is all about. It also informed participants on the "fairytale story" between CCI Europe and SIOPE: how the collaborative relationship started, the current EU projects that they are both involved in and how they are successfully scaling up childhood cancer initiatives in Europe.

At the Market Place, everyone attending the conference also had the opportunity to introduce their own organizations. This enabled everyone to get to know each other better and to identify shared interests and common challenges.

Among the key topics covered in the conference was: Fundraising and Public Relations, Parents Involvement in Research and Drug Development,



Best Practices and Good Practice models of parents organizations and survivor focused organizations, Quality of Life and Importance of Long Term Follow Up of Survivors, on line patient and patient support communities. UNiTE2CURE, a pan European advocacy network, where many CCI members are involved, made a presentation on the advances and successes they have achieved so far.

There was also a parallel mentoring workshop for Survivors - with focus on how different groups are organized, the types of activities they undertake and how peer support is working in their own countries. The conference ended with the emotionally charged and meaningful community singing of the song "We Are One".

OCEANIA - COMING TOGETHER TO ENHANCE SYNERGIES, EFFECTIVENESS, VOICE AND REACH

The first CCI Australia Childhood Cancer Stakeholders Meeting was held in Melbourne, Australia on August, 2016.

It was attended by 25 participants composed of parents, representatives of childhood cancer support organizations and health professionals. The discussions revolved on 3 key topics: what is working, what is not working and what can be changed. The way forward focused on 3 areas: a) need for enhanced synergies, improved communication, coordination and greater collaboration between the various NGOs and childhood cancer support groups, to avoid duplication, increase transparency and ensure better service to families; b) need for childhood cancer support groups to align their programs and services with the stages of childhood cancer care and to provide one on one support so that families receive timely services, "don't get left behind" or "don't get forgotten". This includes expressed need for programs for education of pre-schoolers on extended hospital stay, palliative care, bereavement and follow up care; c) need to have a stronger collective voice when it comes to advocating to government and health institutions.

BOOSTING HOPE AND SCALING UP COLLABORATIVE INITIATIVES IN ASIA

The 10th CCI Asia Conference with the theme "Days of Hope" was held on May 26 – 28, 2016 in the Presidential Building of the Russian Academy of Science, Moscow, Russia.

Due to strict visa requirements, only 60 parents, survivors, and volunteers, representing childhood cancer organizations and support institutions from 12 countries were able to attend. However, there were a number of key sessions where nurses and medical professionals joined the CCI parents, survivors and volunteers, bringing session attendance close to 100. Also noteworthy was the attendance of several local key stakeholders and representatives of childhood cancer focused institutions from various cities and areas of Russia.

The conference success was achieved with exceptional support from the very dedicated and committed team of the local organizing committee of SIOP Asia headed by: Dr. Alexander Rumyantsev (Congress President), Dr. Svetlana Varfolomeeva (Deputy Congress President), Dr. Kirill Kirgizov (Congress Secretary) and the CCI Asia Regional Organizing team members headed by Benson Pau (CCI Asia Regional Head), Ira Soelistyo, Kohsuke Yamashita, Katerina Kiseleva, and Carmen Auste. With the excellent collaboration between the CCI & SIOP Asia team, several new norms for CCI-SIOP Asia conference





standards for collaboration was set. These included engaging CCI Asia survivors and local survivors to have an active role in the joint CCI-SIOP Asia opening and closing ceremonies as well as having joint keynote sessions and innovative learning sessions. The conference was made more inspiring with the attendance of the keynote speaker, Dr. Andreas Ullrich, from WHO Headquarters, Geneva who led the joint WHO-CCI Session on "Improving Access, Availability, Affordability and Safety of Essential Childhood Cancer Medicines". Other presenters and panelists were CCI Chair, Carmen Auste, SIOP Asia President, Dr. Chi Kong Li, UICC President, Dr. Tezer Kutluk and Dr. Kirill Kirgizov.

The presentation by Maruzza Foundation (Professor Marcello Orzalesi and Giovanna Abbiati) on the Trieste Charter of the Rights of the Dying Child as well as the Religions of the World Charter on Pediatric Palliative Care was also a major learning event.

The networking event that was hosted by local members in Moscow was a lively and fun event where members were able to learn about Russian culture, tradition and cuisine as well as get to know each other better.

The first joint SIOP-CCI session on "Late Effects and Survivorship", was another memorable event, especially as the CCI survivors presented as part of the CCI SIOP Closing ceremonies, the Russia CCI ASIA Survivors Consensus Statement building on The Survivors Declaration of Jogjakarta, Indonesia (2012). The conference participants all stood up and gave the survivors a rousing applause after their presentation. They also approached the survivors to express their appreciation of their courage and commitment and to wish them continued good blessings for their future.

The host country for the CCI Asia May, 2017 conference is Thailand. The theme is Optimizing Care for Asian Childhood Cancer. The Thai Pediatric Oncology Group is the local organizing committee for the conference while the CCI member host organization is Wishing Well headed by Dr. Issarang Nuchprayoon.

AFRICA

The 4th CCI Africa Regional Conference (and 12th SIOP) will take place in Marrakesh, Morocco, from 5 – 8 April 2017. CCI founding member, L' Avenir, is part of the organizing committee while CHOC SA (South Africa) has committed both financial and technical support for the conduct of the conference. At least 10 countries are expected to attend. The CCI Board Mid-Year Board Meeting is also planned to be held prior to the regional conference to enable the board members to personally meet and interact with CCI Africa members and other key regional stakeholders. A networking dinner will be hosted by CCI with financial support by CHOC SA, CCI anchor organization in Africa.

LATIN AMERICA

The 2017 Regional Meeting will be held in the Dominican Republic from August 22-25.

Representatives from at least 20 different organizations in 10 different countries (Argentina, Colombia, Panama, Haiti, Venezuela, Costa Rica, Mexico, Ecuador, Dominican Republic and Chile) are expected to attend in addition to other non CCI members.

THE CCI AND INTERNATIONAL SOCIETY OF PAEDIATRIC ONCOLOGY (SIOP) 2016 INTERNATIONAL CONFERENCE

Childhood Cancer Foundation, CanCare4Living, CanTeen Ireland and Barretstown as local members of Childhood Cancer International, co-hosted the Parents and Survivors/Childhood Cancer International Track of the 48th Congress of The International Society of Paediatric Oncology (SIOP) which took place in Dublin from the 19th to the 22nd of October 2016.



It was the first time the world's leading paediatric congress was held in Ireland, offering a unique opportunity for clinicians, scientists, nurses, allied health professionals, parents and survivors, to engage with colleagues from across the globe and for parents and survivors to access international expertise on cancer treatments, drug trials, research and also on the evolving area of survivorship issues.

Over the course of 4 days, 2,336 registered delegates from 100 countries had meaningful conversations with colleagues, learning from one another about their experiences and the key issues in their countries that affect children and young adults with cancer and their families.

Delegates were given a rare opportunity to have the Meet & Greet in the majestic and historical surroundings of The Long Room Trinity College. This library, dating from 1712, houses more than 200,000 ancient books and manuscripts and is home to the ancient Celtic manuscript, The Book of Kells.

In her opening address to delegates at the CCI Meet and Greet, Carmen Auste, Chairperson of Childhood Cancer International, quoted an old Irish Proverb,

Trína chéile a thógtar na caisleáin which translates, "In our togetherness, castles are built". She encouraged delegates to interact and engage fully in all the conference activities: DREAM BIGGER, INNOVATE, and INSPIRE EACH OTHER to DO MORE for children/adolescents with cancer, survivors and their families.

The Gala and Networking dinner was held at Smock Alley Theatre Banquet Hall, the first Royal Theatre built in Dublin and opened in 1662. Music by Alan and Jenny, herself a childhood cancer survivor was enjoyed by all.

The inspiring and memorable evening concluded with a group rendition of Child4Child's We are One, led by a young survivor from Indonesia and CCI Board Treasurer, Poonam Bagai.



The CCI Board were hosted for their Annual Board meetings at the Irish Cancer Society and by CCI member and co host Barretstown, at their camp facility at Barretstown Castle in Co Kildare, where they had the opportunity to see and experience a family weekend camp.

ICCD ADVOCACY AND PUBLIC EDUCATION LEARNING MATERIALS

In collaboration with CLAN-Australia and NCD-CHILD, CCI developed a rights based flyer concretizing in simple terms and practical action what the rights of children with cancer are based on the United Nations Declaration on the Rights of Children.

This material was used by CCI members to supplement the advocacy material 8 Reasons Why Children/ Adolescents with Cancer Deserve our Attention. These materials have been translated and localized by a number of CCI member organizations in Asia, Africa and Latin America.

For ICCD 2017, a Global Childhood Cancer Infographic will be launched to assist members in advocacy and public education. For the International Childhood Cancer Survivors Month in June, 2017, an Infographic on Childhood Cancer Survivors: Myths and Facts and What You Can Do About It will be launched together with a Survivorship Teaser Video.





THE DECLARATION OF DUBLIN, IRELAND

Surviving childhood cancer can be a lifelong challenge, regardless of geographical, religious, ethnic, financial and cultural backgrounds. We, the global CCI Survivors Network, ask medical and psychosocial professionals and all other stakeholders to acknowledge the challenges and needs of survivors.

Survivors of childhood cancer may develop medical and psychosocial late effects that severely impact their quality of life. Therefore, comprehensive long-term follow-up care is essential. We ask that adequate long-term follow-up clinics are established, where survivors can have access to personalized follow-up care. We ask for more research on late effects so that survivor care services can be improved.

Inadequate transition from childhood cancer care to adult medical care can result in a lack of knowledge and understanding of the impact and consequences of childhood cancer by the treating health professional(s). It is essential that these health professionals have a thorough understanding of the needs of cancer survivors. We request for full disclosure and sharing of our medical history and potential risks to our current and future health.

We emphasize the importance of trustworthy and empathetic psychosocial support during and after treatment. We ask all involved with our long-term care to be forthcoming and honest with us and to take our issues seriously.

In some countries, survivors are stigmatized and experience discrimination. We ask for equal opportunities in society including, but not limited to, education, employment and insurance.

Although cancer is a major cause of death amongst children around the world, it is important to convey to the general public that childhood cancer is often curable and that the survivors' population is increasing globally each year. We urge you to work with us to educate the general public in order to dispel misconceptions and myths about childhood cancer.

With the support and commitment of all stakeholders, childhood cancer survivors can be actively engaged in society and live their lives to the fullest.

Dublin, October 18th 2016

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SHINING A LIGHT ON SURVIVORS INITIATIVES, NEEDS AND CONCERNS



DECLARACIÓN DE DUBLÍN, IRLANDA

Sobrevivir a un cáncer en la infancia o adolescencia puede ser un desafío para toda la vida, independientemente de los antecedentes geográficos, religiosos, étnicos, financieros y culturales. Nosotros, la Red Global de Supervivientes de la CCI, pedimos a médicos, profesionales de la salud, psicólogos, trabajadores sociales y a todos los agentes implicados que reconozcan los desafíos y necesidades de los supervivientes.

Los supervivientes de cáncer infantil pueden manifestar efectos tardíos (después del alta) relacionados con su salud, física, emocional o psicológica, que produzcan un impacto serio en su calidad de vida. Por ello, es imprescindible un seguimiento multidisciplinar a largo plazo. Pedimos que se establezcan consultas de seguimiento a largo plazo en las que los supervivientes tengan acceso a una atención personalizada. Además, pedimos que se investigue más sobre los efectos a largo plazo, para mejorar la asistencia a los supervivientes.

Una inadecuada transición desde la atención médica en las unidades de oncología pediátrica a la posterior atención médica en los servicios de adultos puede llevar al desconocimiento y a la falta de comprensión del impacto y las consecuencias del cáncer infantil por los profesionales de la salud. Por ello, es esencial que estos profesionales conozcan las necesidades de los supervivientes de cáncer. Pedimos que nos proporcionen una información completa de nuestro historial médico y de los posibles riesgos en nuestra salud actual y futura.

Enfatizamos la importancia de un apoyo psicosocial de confianza y empático hacia nuestra problemática, tanto durante como después del tratamiento. Pedimos que todos los involucrados en nuestro seguimiento a largo plazo sean accesibles y honestos con nosotros y se tomen en serio nuestras cuestiones.

En algunos países, los supervivientes son estigmatizados y discriminados. Pedimos igualdad de oportunidades en la sociedad incluyendo, entre otros, educación, empleo y seguros.

Aunque el cáncer es una de las principales causas de muerte en los niños de todo el mundo, es importante transmitir a la opinión pública que el cáncer infantil es frecuentemente curable y que la población de supervivientes crece a nivel mundial cada año. Les instamos a trabajar con nosotros sensibilizando a la sociedad en general, para eliminar los mitos y las ideas equivocadas sobre el cáncer infantil.

Con el apoyo y el compromiso de todos, los supervivientes de cáncer infantil podrán participar activamente en la sociedad y vivir plenamente sus vidas.

Dublin, 18 de Octubre de 2016



CCI ASIA SURVIVORS CONSENSUS STATEMENT

(delivered at the closing ceremonies of the 2016 SIOP-CCI Asia Conference in Moscow, Russia)

The completion of treatment is not really the end of battling childhood cancer. It is just the beginning of new challenges and diverse difficulties which keep us from living happy, meaningful and productive lives.

Thus, the survivors of Asia ask you to inform and educate parents, survivors, medical professionals and the community about late effects and how it impacts the lives of survivors.

We also urge you to work with us in breaking misconceptions and false beliefs about childhood cancer. At times, we feel people look at us as if we are not normal, as if we are not capable and as if we are not part of the community. We currently experience discrimination in employment, getting insurance coverage and opportunities for advanced education and training. We need your help to advocate for reforms and changes in laws so we can fully and freely be who we are and become the best we can be.

We believe that as survivors, having conquered childhood cancer, we can be as strong, talented and successful as anybody, if you support us and be with us.

We ask you to make available additional resources, programs and services to help us build, grow and maximise our skills and talents.

We also ask you to create and strengthen follow up care clinics and services to ensure quality healthcare to survivors on their lifelong journeys.

Finally, it is important that survivors feel that they are not alone. We encourage you to create opportunities for survivors to come together, inspiring and nurturing each other. We invite all of you to SPEAK OUT and STAND UP for survivors as we all know -

TOGETHER, UNITED, WE ARE STRONGER!

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SHINING A LIGHT ON SURVIVORS INITIATIVES, NEEDS AND CONCERNS



KIDSCAN KONNECT (KCK) FELLOWSHIP PROGRAM IN INDIA

Childhood Cancer survivors join Kidscan Konnect at the age of 13 and above. Survivors start off as KCK members, then become Active members, Leaders and Mentors, according to the work they have done. They offer peer support to each other, learn to look after their health and cope with late side effects of their cancer treatment. They participate in awareness programs and motivate younger childhood cancer patients. Increasingly they are participating in late side effect research studies and projects.

Under a burgeoning CanKids Fellowship program, that offers internships and employment opportunities, they reintegrate into society. They also become Childhood Cancer Advocates and Ambassadors. The first intern was placed under the CanKids Awareness and Advocacy Program in 2013. This was a pilot initiative to observe whether the survivors would be able to build themselves up according to their skill and talent.

In 2016, the program expanded even more. The KCK leadership/internship program is designed to overcome challenges that childhood cancer survivors experience at various educational levels, all the way to university and graduate school. While providing KCK survivors with additional education and opportunities to further develop necessary work skills, this program also enables KCK survivors to build relationships and more successfully find work in professional organizations.

The Aim of the CanKids-KCK fellowship is to: a) build leadership skills, b) nurture survivors into becoming childhood cancer ambassadors, c) enable survivors to reintegrate into society armed with essential skill sets/competencies, d) help the fellows become more self-aware and enhance their confidence.

To date, 23 survivors have completed internship with CanKids. Fourteen (14) survivors are currently working as employees of CanKids while 7 survivors are interns in 5 states of India.



CHOC AFRICA SURVIVORS INITIATIVES

In South Africa, CCI anchor organization CHOC initiated the formation of the Childhood Cancer Network in SA (CCNSA) with an initial membership of 36 childhood cancer NGOs. During one of the national meetings, survivorship and the challenges to maintain an active survivors group was discussed.

Childhood Cancer Survivor and Olympic Swimmer Romina Armellini led the discussion around survivorship focusing on the challenges and psychological issues of survivorship. Members of the network then decided to collaborate in working together to work on survivorship issues.

In September, 2016, CHOC survivors spearheaded a panel discussion during a Survivors Summit that was held in Cape Town.

The Survivors' Programme in South Africa is growing. CHOC Managers involve survivors in speaking and sharing at schools, wellness days and other special events; many of the survivors experiential stories are featured in newspaper and magazine articles. In East London, 23 year old childhood cancer survivor, Morne Julyan does ward visits and speak to the mothers. Morne became a CHOC Cow, ran his first Comrades Marathon and got excellent media coverage for CHOC and The Cows™.

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SURVIVORS WEEK SPURS THE GROWTH OF SURVIVORS GROUPS IN SPAIN

For the second year in a row, in celebration of International Childhood Cancer Survivors Week (ICCSW), Federación Española de Padres de Niños con Cáncer (FEPNC), organized a gathering of survivors from all over Spain.

Since its launch by CCI in June 2015 (<http://www.childhoodcancerinternational.org/international-childhood-cancer-survivors-week-iccsw/>), ICCSW continue to provide opportunities for survivors to come together, celebrate their victory over cancer and share their experiences. Learning sessions allow them to share ideas, identify common interests and explore future shared initiatives. The survivors group "Caminantes Aspanion" from Valencia launched a new webpage and Facebook during ICCSW 2016, so as to strengthen their on line presence and open up more opportunities for communication and on line interaction among survivors <http://caminantes.aspanion.es/>.

In line with the 2016 ICCSW theme, they have also recorded a video talking about cancer and how childhood cancer has changed their lives; the title of the video is "Juntos somos más Fuertes" (Together Stronger (<https://www.youtube.com/watch?v=FhPsnkA7cMc>)). They plan to translate this into English for the subtitles and eventually into French and German.

To support ICCSW call out for sharing inspirational survivor stories, they uploaded stories of survivors into their Facebook account. Survivors have also been very involved in the ICCD and Light Up Hope Campaigns and plan to create promotional videos for it.

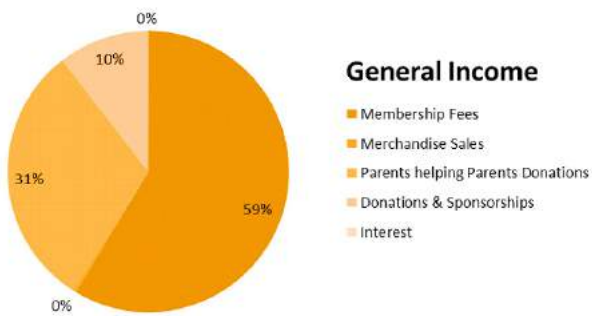
At present, the survivors group in Spain has grown from 4 to 10 and the enthusiasm and energy of the organized groups are exemplary.

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SHINING A LIGHT ON SURVIVORS INITIATIVES, NEEDS AND CONCERNS

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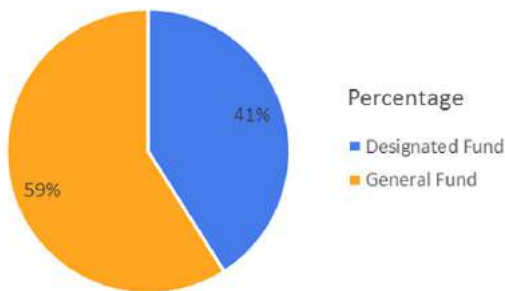
FINANCIAL REVIEW



INCOME

Total income during the year of review 2016 was €121117 against budget of 107,780 - +11% and income of 2015 - €91290 +38%

Of total income of €121117, 59% - €70285 is General Funds and 41% - € 52391 is Designated Funds and Restricted Grants.



INCOME - GENERAL FUNDS

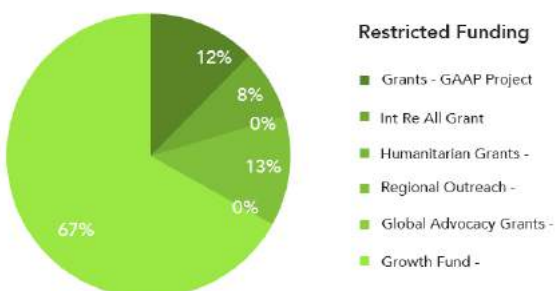
Membership fees accounted for 59% and Parents Helping Parents Fund and other donations and sponsorships for 41% of general funds.

General Fund Income during the year 2016 has increased overall by €1868 which is around 3% higher than 2015 but 3% lower than budget.

The increase in general income is primarily due to 60% increase in PHP Donations from €14575 in 2015 to €21487 in 2016.

Donations and Sponsorships went down from €10176 to €7304.

Membership fee collections went down by 3% from €42405 to €41191.



INCOME - DESIGNATED FUNDS AND RESTRICTED GRANTS

Overall restricted funds and designated project funds went up from € 22872 to €52391 - higher by 130% from 2015 due to Asia Growth funds.

Funds were received in Asia Growth Fund of €35000 from PKW Foundation.

STATEMENT OF FINANCIAL POSITION

The Year 2016 ended with a Surplus of €30165 as against a deficit of €35807 in 2015.

- Accumulated surplus went up by 27% up from €110201 to €140366 due to the surplus of €30165 we ended with.
- Year 2016 ended with total assets of €221,156 as compared to €189,861 for year 2015.

We are grateful to

PPPH Donors		General Donors		Pro bono Services
Deutsche Leukamie-Forschungshilfe-Germany	5000	Billull Nordea Bank	5000	1. Simon Lala, Chief Financial Officer (Lala & Lala Associates New Zealand)
Germany Elternhilfe Gottingen-Germany	10000	France Eurodis	1650	2. Chandan Kumar , CCI Survivor Support Services Coordinator (Cankids -Kidscan , India)
Kinderkrebshilfe Schweiz-Switzerland	1000	Osterreichische Kinder - Krebs-Hilfe	500	3 Marcela Zubieta and her communications team headed by , Oscar Barbaste for the newsletter production (Fundacion Nuestros Hijos , Chile)
Kids Cancer Care Foundation of Alberta - Canada	478	Others (small)	154	4. Stephanie Schremmer CCI Europe Regional Committee support/focal person (Kinderkrebshilfe, Austria)
Pau Kwong Wun Charitable Foundation- Hong Kong	500	Total	7304	5. Christijana So, CCI Asia Regional Committee support/focal person (PKW Foundation, Hong Kong,China) 6. PKW Foundation, Hong Kong, China and Benson Pau for printing of CCI Annual Report 7. Roseann Alvaro (Cancer Warriors Foundation, Philippines for support to CCI Chair)
National Cancer Society Malaysia-Malaysia	600	CCI Asia Growth Fund – PKW Foundation – HongKong (from 2013 Every Child Deserves A Chance campaign during 2013 CCI /SIOP International Conference in Hongkong , China)	35000	8. All Board Members and Regional Committee Members
Childrens Cancer Assoc. Of Japan	600			9. Garbergs
CHOC -Childhood Cancer Foundation-South Africa	3309			10. ACCO support for advocacy travel and accommodations of Ruth Hoffmann 11. My Room and Mary Mc Gowan support for travel and logistics related requirements of CCI Board
Total	21487		42304	12. 12. CCI Head office -The Board of VOKK, Niuwegian Netherlands and Marianne Naafs Wilstra

STATEMENT OF FINANCIAL PERFORMANCE FOR THE PERIOD ENDED 31 DECEMBER 2016

	<i>Note</i>	<i>2016</i>	<i>2015</i>
INCOME			
Membership Fees		41,191	42,405
Merchandise Sales		250	941
Parents helping Parents Donations		21,487	14,575
Donations & Sponsorships		42,304	10,176
Interest		<u>52</u>	<u>320</u>
		105,285	68,417
RESTRICTED FUNDING			
Grant- GAAP Project		6,564	7,946
Int Re All Grant		4,184	6,367
Humanitarian Grants			2,133
Regional Outreach		6,643	
Global Advocacy Grants			<u>6,427</u>
		<u>17,391</u>	<u>22,872</u>
TOTAL INCOME		122,676	91,289
EXPENSES			
<i>Administration Costs</i>			
Audit Fees		994	750
Bank Charges		761	2,342
Executive Meeting Costs		19,089	18,960
General Expenses		1,622	813
Insurance		575	
Legal Fees			5,035
Secretariat Expenses		<u>20,630</u>	<u>17,867</u>
		43,670	45,768
<i>Fundraising Costs</i>			
Merchandise Purchases		1,028	274
<i>Programs Cost</i>			
A. GA Meeting Expenses		1,005	531
International Congress Scholarships		9,454	12,876
Advocacy & Lobbying		5,246	24,254
Asia Growth Fund Expenses		990	
GAAP Expenses		6,564	7,946
Int Re All Project Costs		4,184	6,367
Marketing & PR		5,933	7,614
Nepal Humanitarian Grant			2,106
Regional Meetings		7,795	16,200
Regional Outreach		<u>6,643</u>	<u>3,160</u>
		<u>47,813</u>	<u>81,054</u>
TOTAL EXPENSES		<u>92,512</u>	<u>127,096</u>
NET SURPLUS (DEFICIT)		€30,165	€(35,807)

The accompanying notes form part of these financial statements.

Lala & Associates
Chartered Accountants



STATEMENT OF MOVEMENTS IN ACCUMULATED FUNDS FOR THE PERIOD ENDED 31 DECEMBER 2016

	Note	2016	2015
Surplus (Deficit) for the Period		30,165	(35,807)
<i>al Recognised Revenue and Expenses</i>		30,165	(35,807)
VERAL FUNDS AT START OF PERIOD		110,201	146,008
		140,366	110,201
VERAL FUNDS AT END OF PERIOD		€140,366	€110,201

STATEMENT OF FINANCIAL POSITION AS OF 31 DECEMBER 2016

	Note	2016	2015
ACCUMULATED FUNDS			
Accumulated Surplus		€140,366	€110,201
CURRENT ASSETS			
Credit Card Deposit		1,002	-
Euro A/c - Netherlands		8,963	19,374
Int Re All Bank A/c		12,204	16,388
Prepayments		-	7,500
Euro Saving Account		5,850	5,843
Term Deposits		184,995	137,374
Accounts Receivable		1,740	924
GAAP Bank A/c		6,402	2,458
TOTAL ASSETS		221,156	189,861
		221,156	189,861
CURRENT LIABILITIES			
Accounts Payable		10,071	3,556
Unspent Project Grants		70,719	76,103
TOTAL LIABILITIES		80,790	79,660
		80,790	79,660
NET ASSETS		€140,366	€110,201

Carsten V. Cuete

Chairperson

Boga

Treasurer

August 23, 2017

Date

Aug 23, 2017

Date

Organization (183)	Country (93)	website			
Centro de Apoyo al Enfermo de Leucemia (CENAELE)	ARGENTINA	www.cenaele.org.ar	British Columbia Childhood Cancer Parents Association (BCCCPA)	CANADA	www.bcccpa.org
Fundación Creando Lazos (FCL)	ARGENTINA	www.creandolazos.org.ar	Childhood Cancer Canada Foundation	CANADA	www.childhoodcancer.ca
Fundación Crisalida	ARGENTINA	www.fundacioncrisalida.org	Kids Cancer Care Foundation of Alberta (KCCFA)	CANADA	www.kidscancercare.ab.ca
Fundación Mateo Esquivo	ARGENTINA	www.fme.org.ar	Kids with Cancer Society Northern Alberta	CANADA	www.kidswithcancer.ca
Fundación Natalí Dafne Flexer	ARGENTINA	www.fundacionflexer.org	Fundación Nuestros Hijos	CHILE	www.fnh.cl
Friends of Children with Cancer	ARMENIA	www.children@am	Children's Cancer Foundation	CHINA	www.ccf.org.hk
Childhood Cancer Support Inc.	AUSTRALIA	www.ccs.org.au/	Guangzhou Gold-ribbon Special Children Parents Centre	CHINA	www.jiazhanghui.org.cn
Children's Cancer Centre Parent Advisory Committee (PAG)	AUSTRALIA	www.rch.org.au/ccs	Little Life Warrior Society	CHINA	www.hklws.org/en_index.php
Österreichische Kinder-Krebs-Hilfe	AUSTRIA	www.kinderkrebshilfe.at	Pau Kwong Wun Charitable Foundation	CHINA	www.pkwfoundation.org
Charter of "Fighting Leukemia" public union	AZERBAIJAN	www.leykoz.az	Asociación Alianza para la prevención y el tratamiento del cáncer en el niño-sanar (SANAR)	COLOMBIA	www.sanarcancer.org
ASHIC Foundation for Childhood Cancer	BANGLADESH	www.ashic.org	Colombian Leukemia and Lymphoma Foundation (FCL)	COLOMBIA	www.funleucemialinfoma.org/
Children Leukemia Assistance & Support Services (CLASS)	BANGLADESH	www.classbd.org , www.facebook.com/classbd	Fundación la Divina Providencia	COLOMBIA	www.fundacionladivina providencia.org
Fundación AFANIC	BOLIVIA	www.fundacionafanic.com	Fundación María José, Pequeños y Grandes Heroes (FMJ)	COLOMBIA	www.fundacionmariajose.org
Udruženje roditelja djece oboljele od malignih bolesti „Iskra“ ISKRA Banjaluka; The Association of Parents of children with malignant diseases "The spark" Banjaluka	BOSNIA & HERZEGOVINA	www.udrrodiskrabl.com	Fundación Organización de Padres de Niños con Cáncer - OPNICER	COLOMBIA	www.opnicer.com
Udruženje "Srce za djecu koja boluju od raka u FBiH" (The heart for the kids with cancer in FBiH)	BOSNIA & HERZEGOVINA	www.srcezadjecu.ba	Pohema Foundation	COLOMBIA	www.pohema.org
Casa de Apoio a Criança com Câncer São Vicente de Paulo	BRAZIL	www.casaapoio cancer.org.br	Asociación Naninu de padres de niños can cancer (NANINU)	COSTA RICA	www.proyectonaninu.com
Núcleo de Apoio à Criança com Câncer (NACC)	BRAZIL	www.nacc.org.br	Fundación GiáMaLa de jóvenes para jóvenes	COSTA RICA	www.giamala.com
Association "Children with Oncohematologic diseases"	BULGARIA	www.decaohz.org	Krijesnica (Firefly)	CROATIA	www.krijesnica.hr
North West Childhood cancer Parent organisation in Cameroon (NWCCPOC)	CAMEROON	http://cbcchildhoodcancer.com/partners.html	Ljubav na Djelu (Love in Action)	CROATIA	www.ljubavnadjelu.hr
b.r.a.i.n.child (Brain Tumour Research, assistance and Information Network)	CANADA	www.sickkids.ca/brainchild	Sanus	CROATIA	www.sanus.hr
			Sdružení Šance	CZECH REPUBLIC	www.sancecz.org
			Børnecancerfonden	DENMARK	www.boernecancerfonden.dk
			Familier med kræft ramte børn (FMKB)	DENMARK	www.fmkb.dk
			Fundación Amigos contra el cancer Infantil, Inc. (FACCI)	DOMINICAN REPUBLIC	www.facci.org.do
			ASONIC – QUITO	ECUADOR	www.asonic.org

7 THE CCI FAMILY OF MEMBER ORGANIZATIONS

Jóvenes Contra el Cáncer Fundación	ECUADOR	www.jovenescontraelcancer.org	St. Jude India Childcare centres	INDIA	www.stjudechild.org
Sol y Vida Fundación	ECUADOR	https://es-la.facebook.com/fundacion.soldevida	Indian Cancer Society (ICS)	INDIA	www.ugamcalling.org ; www.indiancancersociety.org
Alexandria Group of Childhood Cancer Care (AGCCC)	EGYPT		ImPaCCT foundation	INDIA	www.impacctfoundation.com
Mathiwos Wondu - YeEthiopia Cancer Society (MWECS)	ETHIOPIA	www.mathycancersoc.org	Yayasan Anyo Indonesia (YAI) - The Indonesian Anyo Foundation	INDONESIA	www.yai-indonesia.org
Tesfa Addis Parents Childhood Cancer Organization	ETHIOPIA	Under Construction	Indonesian Care for Cancer Kids Foundation (Yayasan Kasih Anak Kanker Indonesia, YKAKI)	INDONESIA	www.ykaki.or.id/
SYLVA	FINLAND	www.sylva.fi	Yayasan Onkologi Anak Indonesia (YOAI, Indonesian Childhood Cancer Foundation)	INDONESIA	www.yoaifoundation.org
L'ENVOL pour les enfants européens	FRANCE	www.lenvol.asso.fr	Yayasan Sentuhan Kasih Anak Indonesia possible change of name to Yayasan Kanker Anak Indonesia	INDONESIA	-
Union Nationale des associations de Parents d'Enfants atteints de Cancer ou Leucémie (UNAPECCLE)	FRANCE	http://www.unapeccle.net	Society to Support Children Suffering from Cancer (MAHAK)	IRAN	www.mahak-charity.org
International Support Fund for the Children Suffering from Leukemia (support Fund)	GEORGIA	www.fund.8m.com	Children of Cancer human Organization	IRAQ	-
Deutsche Leukämie-Forschungshilfe (DLFH)	GERMANY	www.kinderkrebsstiftung.de	Kurdistan Save the Children (KSC)	IRAQ	www.ksc-kcf.org
Ghana Parents association for Childhood Cancers (GHAPACC)	GHANA	www.ghapacc.org	Barretstown Camp	IRELAND	www.barretstown.org
Floga - Parents association of Children with Cancer	GREECE	www.floga.org.gr	CanCare4Living	IRELAND	www.cancare4living.ie
Panhellenic association of Childhood and Adolescence Cancer Survivors	GREECE	www.tokyttaro.gr	CanTeen Ireland, Young People's Cancer Support Group	IRELAND	www.canteen.ie
Fundación Ayúdame a Vivir	GUATEMALA	www.ayuvi.org.gt	Childhood Cancer Foundation (CCF (Light it up Gold))	IRELAND	www.childhoodcancer.ie
Fundación Hondureña para el Niño con Cancer (Honduras Foundation for children with cancer)	HONDURAS	www.salvamivida.org	Hayim association for children with cancer in Israel	ISRAEL	www.hayim.org.il
Európai Támogatási Egyesület a Rákos Gyermekéért	HUNGARY	www.euroonko.de	Federazione Italiana associazioni Genitori Oncoematologia Pediatrica (FIAGOP)	ITALY	www.fiagop.it
Styrktarfélag Krabbameinssjúkra Barna	ICELAND	www.skb.is	Fondazione Cure2Children	ITALY	www.cure2children.org
Cancer Patients Aid association (CPAA)	INDIA	www.cancer.org.in	Soleterre strategie di pace ONLUS	ITALY	www.soleterre.org
Aroh-Giving Hope	INDIA	www.arohonline.org/	Asian Children's Care League (ACCL)	JAPAN	www.accl.jp
Cankids...kidscan	INDIA	www.cankidsindia.org	Children's Cancer Association of Japan (CCAJ)	JAPAN	www.ccaj-found.or.jp
Eeshwar Child Welfare Foundation (ECWF)	INDIA	http://eeshwarchildwelfare.org/	Shine On! Kids	JAPAN	www.sokids.org
Nivethan	INDIA	www.nivethan.org	King Hussein Cancer Foundation and Center/ Awn Parents' Support Group	JORDAN	www.khcf.jo
Sahayta Charitable Welfare Societv	INDIA	http://cancersahayta.com			

Childhood Cancer Initiative	KENYA	www.childhoodcancerinitiative.org	Vereniging Ouders, Kinderen en Kanker' (VOKK)	NETHERLANDS	www.vokk.nl ; www.koesterkind.nl (palliative); www.kankerketting.nl ; www.vox.nl (survivors)
Hope for Cancer Kids	KENYA	www.hope4cancerkids.org	Child Cancer Foundation	NEW ZEALAND	www.childcancer.org.nz
CHANCE association	LEBANON	www.chanceassociation.org	Asociacion de Padres de Ninos Con Leucemia y Cancer (MAPANICA)	NICARAGUA	MAPANICA, facebook
Children's Cancer Center of Lebanon (CCCL)	LEBANON	www.cccl.org.lb	Children Living with Cancer Foundation (CLCWF)	NIGERIA	www.clwcf.org
Kids First association	LEBANON	http://www.kidsfirstassociation.org/	Simara Children Cancer Foundation (SCCaF)	NIGERIA	www.simaraccf.org
Paguoda	LITHUANIA	www.paguoda.org	Barnekreftforeningen (The Norwegian Childhood Cancer Organization)	NORWAY	www.barnekreftforeningen.no
Een Häerz fir kriibskrank Kanner asbl	LUXEMBOURG	www.kriibskrankkanner.lu	Foundation Smile of Hope (SOH)	p/a ISRAEL (PALESTINE)	www.smileofhope.org
Fondatioun Kriibskrank Kanner	LUXEMBOURG	www.fondatioun.lu	Cured Cancer Patients Society (CCPS) - Tiger Team Cancer Fighters	PAKISTAN	www.tigerteampk.org
Peperutka	MACEDONIA	www.peperutka.org.mk	Fundación amigos del niño con leucemia y cancer (FANLYC)	PANAMA	www.fanlyc.org.pa
Children's Cancer Club	MALAWI	www.childrenscancermalawi.org	MITAI - Asociación para Ayuda y Sostén de Niños con Cáncer	PARAGUAY	-
Cancer Survivors Quest (CSQ)	MALAWI	under construction	Asociación de padres de niños con cáncer (ASPAÑION)	PERU	www.aspañion.org
National Cancer Society Malaysia	MALAYSIA	www.cancer.org.my	Cancer Warriors Foundation Inc	PHILIPPINES	www.c-warriors.org
Sarawak Children's Cancer Society (SCCS)	MALAYSIA	www.sccs.org.my	Kythe Foundation Inc.	PHILIPPINES	www.kythe.org
Aquí Nadie Se Rinde, IAP	MEXICO	www.aquinadieserinde.org.mx	Acreditar	PORTUGAL	www.acreditar.org.pt
Asociacion Mexicana de Ayuda a Ninos con Cancer, I.A.P. (AMANC)	MEXICO	www.amanc.org	AMURADIA association	ROMANIA	www.zambet-de-copil.ro
CANICA (Centro de apoyo a ninos con cancer A.C.)	MEXICO	www.canica.org.mx	Association P.A.V.E.L.	ROMANIA	www.asociatiapavel.ro ; www.e-scoaladespital.ro/
Familias Quánticas A.C.	MEXICO	www.familiasquanticas.org	Asociația Impreună pentru copiii cu cancer	ROMANIA	www.ipcc.ro
Proayuda a Niños con Cáncer Luz de Vida, A.C.	MEXICO	www.luzdevida.org.mx	Triedinstvo	RUSSIA	www.triedinstvo.edu.severodvinsk.ru
FENIX MONTENEGRO' NGO' association of parents of children with children's cancer (FENIX MONTENEGRO)	MONTENEGRO	www.fenixnvo.me	Children and parents against cancer (CAPAC)	RUSSIA	www.capac.ru
AMAL (association des maladies atteints de leucémies) see remark at end of line	MOROCCO		ISKORKA	RUSSIA	
L'association L'Avenir	MOROCCO	www.lavenir.ma	Social Charitable Foundation for Help to Children suffered from leukemia	RUSSIA	www.angela-vavilova.ru
Noujoum	MOROCCO	www.noujoum.org	The Holiday of Life Charity fund	RUSSIA	www.hollife.ru/blago
Namibia Childhood Cancer Parents Support Organisation (NaCCapso)	NAMIBIA	-	ASEAC (association Senegalaise de Soutien aux Enfants Atteints de Cancer)	SENEGAL	
Cancer Council Nepal (CCN)	NEPAL	http://cancercouncilnepal.org.np/			
Cancer Society Nepal	NEPAL	www.cancersocietynepal.org.np			
Children Cancer Foundation Nepal (CCFN)	NEPAL	www.ccfnepal.org			



"ČIKA BOCA" Childhood Cancer Parent Organization	SERBIA	www.cikaboca.org ; www.mlalice.org	ZOE4LIFE	SWITZERLAND	www.zoe4life.org
"ZVONČICA" Childhood Cancer Parent Organization	SERBIA	www.zvoncica.org.rs	BASMA (Battling to SMile Again) Children with Cancer Support association	SYRIA	www.basma-syria.org
Udruzenje "Uvek sa decom" (association "Always with children")	SERBIA	www.sadecom.org.rs	Tumaini la Maisha Tanzania	TANZANIA	www.wearetim.org
NURDOR (Nacionalno Udruzenje Roditelja Dece Obolele od Raka)	SERBIA	www.nurdor.org.rs	Wishing Well Foundation	THAILAND	www.wishingwellthai.org
Rowaca Cancer Group - Sierra Leone (RCG-SL)	SIERRA LEONE	rowacacancersl.webs.com/	Child Cancer Foundation of Tonga	TONGA	www.ccf.t
Children's Cancer Foundation (CCF)	SINGAPORE	www.ccf.org.sg	The Just Because Foundation	TRINIDAD & TOBAGO	http://thejustbecausefoundation.com
Detom s rakovinou n.o. - For Children with Cancer	SLOVAKIA	http://www.detomsrakovinou.sk/	LÖSEV	TURKEY	www.losev.org.tr ; www.losev.org.tr/v2/en/
SMILE, n.o., POMÁHAME S ÚSMEVOM	SLOVAKIA	www.lifesupport.sk	Bless a Child Foundation	UGANDA	www.blessachildfoundation.org
JONATAN PRIJATELJ (Jonatan friends)	SLOVENIA		Charitable Fund VIDEN	UKRAINE	No website
CHOC Childhood Cancer Foundation South Africa	SOUTH AFRICA	www.choc.org.za	Childhood Cancer Foundation "Crab"	UKRAINE	http://krab.org.ua/eng/
Korean association for Children with Leukemia and Cancer (KALC)	SOUTH KOREA	www.soaam.or.kr	David Deacon Charity Institution	UKRAINE	www.ukrainischekinderkrebshilfe.de
Federación Española de Padres del Niños con Cáncer (F.E.P.N.C.)	SPAIN	www.cancerinfantil.org	Charitable Foundation Zaporuka	UKRAINE	www.zaporuka.com.ua ; zaporuka.org.ua
Barncancerfonden	SWEDEN	www.barncancerfonden.se	Childhood Cancer Parents Alliance (CCPA)	UNITED KINGDOM	www.ccpa.org.uk
Barncancerfonden Norra	SWEDEN	www.barncancerfonden.se/Norra	CLIC Sargent	UNITED KINGDOM	www.clicsargent.org.uk
Barncancerfonden Stockholm Gotland	SWEDEN	www.barncancerfonden.se/stockholm	American Childhood Cancer Organization	UNITED STATES	www.acco.org
Barncancerfonden Mellansverige	SWEDEN	www.barncancerfonden.se/lokala-foreningar/mellansverige	Asociacion Venezolana de Padres de Niños con Cancer (ASOVEPANICA)	VENEZUELA	-
Barncancerfonden Östra	SWEDEN	www.barncancerfonden.se/ostra	FTMO (Fundación para el Trasplante de Médula Ósea)	VENEZUELA	www.ftmovenezuela.org
Barncancerfonden Södra	SWEDEN	www.barncancerfonden.se/lokala-foreningar/sodra/	Childhood Cancer Family Group in Central Vietnam (CCFGCV)	VIETNAM	http://ccfgvietnam.googlepages.com/
Barncancerfonden Västra	SWEDEN	www.barncancerfonden.se/lokala-foreningar/vastra	Kayula Childhood Cancer Foundation (KCCF)	ZAMBIA	(under construction)
association Romande de Familles d'Enfants Atteints de Cancer (ARFEC)	SWITZERLAND	www.arfec.org	Zambian Childhood Cancer Foundation (ZACCAF)	ZAMBIA	www.zaccaf.org (UNDER CONSTRUCTION)
Kinderkrebs Schweiz = Cancer de l'Enfant en Suisse = Cancro infantile in Svizzera = Childhood Cancer Switzerland	SWITZERLAND	www.kinderkrebs-schweiz.ch ; www.cancerenfant.ch ; www.cancroinfantile.ch ; www.childhoodcancer.ch	Kidzcan Children Relief Organisation	ZIMBABWE	www.kidzcanzimbabwe.org
Kinderkrebshilfe Schweiz	SWITZERLAND	www.kinderkrebshilfe.ch	Zimbabwe Parents of Children with Cancer association (ZPCCA)	ZIMBABWE	



8

OUR PROMISE OUR VISION

THIS VISION IS AT THE HEART OF THE PROMISE MADE IN 1992, BY OUR FOUNDING MEMBERS IN VALENCIA, SPAIN.

CCI GLOBAL NETWORK OF MEMBER ORGANIZATIONS, ALLIES AND COLLABORATIVE PARTNERS IS DRIVING CHANGE, CATALYZING ACTION AND WORKING TOWARDS CREATING A WORLD IN WHICH

Children and adolescents with cancer, benefit from the best possible treatment, care and support, anywhere in the world.



the rights to health and well-being of children/adolescents with cancer, the survivors and their families, are protected and promoted.



the challenges faced by children/adolescents with cancer, the survivors and their families, are well understood and fully appreciated by key stakeholders, political leaders, decision makers, societal influentials, healthcare professionals (medical and non-medical), development practitioners and the wider community.



children/adolescents with cancer, the survivors and their families, irrespective of where they are, can readily and easily access affordable, safe, timely, quality care from diagnosis to follow-up support.



1. La mayoría de los cánceres pediátricos tienen curación.



El cáncer infantil causa más muertes que todas las enfermedades pediátricas juntas. **2.**



5.

Contar con una red de apoyo aumenta la esperanza y da más fuerza para hacer frente al cáncer.



3.



La batalla contra el cáncer infantil es un camino largo y lleno de dificultades, que nos cambia la vida para siempre.

4.



Cada menor que supera un cáncer tiene una esperanza de vida media de 71 años.



**Childhood
Cancer
International**

2016 ANNUAL REPORT

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