



ANNUAL REPORT 2021



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1. Message from the President

Alice: Would you tell me, please, which way I ought to go from here?

The Cheshire Cat: That depends a good deal on where you want to get to.

Alice: I don't much care where.

The Cheshire Cat: Then it doesn't much matter which way you go.

Lewis Carroll, Alice in Wonderland

An Annual Report is always an incomplete document: it doesn't mention everything we do, how we do it or the circumstances in which we do it. There will never be a right word, an eloquent text or a creative photograph accurately reflecting the dedication of our entire community to the cause of childhood cancer.

Looking at the Childhood Cancer International (CCI) Annual Report is seeing only a part – sometimes a very small part – of our work in the four corners of the globe. It's not enough to observe a photograph, to read a text or to memorise a fundraiser. Understanding an Annual Report requires a deeper look to what is behind our work: the commitment, the tireless effort, the endless hours of thousands of people speaking the common language of **hope**. People dedicating their time, effort, and competence to the protection and care of those who suffer, who heard a cancer diagnosis too soon in their lives. People unknown to each other, bounded by an invisible thread that we call **service**.

Who we are is a reality that requires a watchful eye. There is an enriching diversity that reflects different ways of looking at life; in fact, the world we live in is made up of different people, with different cultures, with different solutions to dilemmas that are often the same. Even if there is no difference in the anguish with which a parent hears the diagnosis of cancer in a young child, there is a difference in the way each one responds to this terrible challenge. Not only because the inner strength varies – there are no two people alike – but because the circumstances vary as well. We call it **inequities**. The watchful eye will see both realities.

In fact, an unreasonably large number of parents in the world will look at the days after the diagnosis with an aching heart: the lack of financial means, the fragility of social and family networks, the difficulty in accessing essential medicines, the absence of enough human or technical resources, the non-existent or inappropriate government policies that protect parents in their journey. All this will favour early abandonment and poor prognosis. These are some of the factors that influence survival rates in the poorest countries; we must address them to save lives. This is our **commitment** to the future.

It takes a village to raise a child; it surely takes a village to heal a child. This global village – our childhood cancer community – is made up of a multitude of people: volunteers, professionals, health workers, survivors, parents, anonymous people. But it is also made up of organizations with whom we work most closely, who share their technical, scientific, and financial support: WHO, SIOP, St. Jude, Fondation La Roche-Posay, Friends of Cancer Patients, others. CCI is grateful for this global village where we all feel equal, despite all our differences.

The history of CCI is told through a succession of annual reports, not through an isolated annual report. The president who signs an opening text received a testimony from his / her predecessor, who had already received the same testimony. Each president's obligation is to honour this history, to honour the thousands of names engraved in this immaterial token, and hand over a more perfect one to those who will follow.

Cherishing this testimony demands a permanent look to strengths and opportunities, but also to weaknesses. CCI, as all similar organizations, faces permanent challenges: who are we? What do we do? Why do we exist? Do we know which way we ought to go from here? These may seem too philosophical questions, but the answers are vital for our near future. Not for the survival of a simple organisation, but for the survival of the **collective voice** of patients, families, and survivors. The **stronger** we are as an organisation, the stronger our voice will be.

I end with a personal note: last year I referred to the girl whose photograph illustrated the cover of the Annual Report, adding the following caption: *I met the girl whose picture is on the cover a couple of days before she turned one, a couple of days before she was diagnosed with a neuroblastoma. I think the hairless head and the smiling eyes are a good metaphor for what moves CCI: challenge and hope.* The girl on this Annual Report's cover is the same as last year. One year after she is still with us thanks to science and to health professionals, to her own inner strength, to the love of their parents and family. And to hope.

**“Hope” is the thing with feathers -
That perches in the soul -
And sings the tune without the words -
And never stops - at all -**

Even in our most challenging times, even in our most dark hours, may we always cherish in our hearts this thing with feathers that Emily Dickinson spoke about. And may we never forget to say **thank you!** to our global village.



João de Bragança
President, Childhood Cancer International

2. Board of Trustees



PRESIDENT
João de Bragança
Portugal



VICE-PRESIDENT
Rodney Wong
Malaysia



SECRETARY
Luisa Basset
Spain



TREASURER
Nagm Azar
South Africa



MEMBER
Daniel Mckenzie
Zimbabwe



MEMBER
Nicole Scobie
Switzerland



MEMBER
Kate Johnson
Australia



MEMBER
Alejandra Mendez
Chile



MEMBER
Bindu N Nair
India

The Board of Trustees would like to acknowledge the dedication and competence of Simon Lala (current CFO, former president, and honorary member of CCI) and Lex Kuiper (CCI Administrative Officer) that help CCI being more effective and reliable. We would also like to acknowledge the invaluable collaboration of the CCI Regional Committee Chairs and other individuals who put their experience and knowledge at the service of CCI, collaborating with the Board in many ways.



Simon Lala



Lex Kuiper

REGIONAL COMMITTEES

ASIA

| NAME | COUNTRY | ORGANIZATION |
|--------------------|----------------------|---|
| Benson Pau (chair) | Hong Kong SAR, China | Pau Kwong Wun Charitable Foundation |
| Carmen Auste | Philippines | Cancer Warriors Foundation |
| Poonam Bagai | India | Cankids...Kidscan |
| Kazuyo Watanabe | Japan | ACCL (Asian Children's Care League) |
| Saideh Ghods | Iran | MAHAK |
| Kohsuke Yamashita | Japan | CCAJ (Children's Cancer Association of Japan) |
| Ira Soelistyo | Indonesia | YKAKI |
| Roula Farah | Lebanon | CHANCE |

| | | |
|------------------------------------|-----------------|--|
| Bindu Nair | India | Aroh |
| Gary Ho | Malaysia | Sarawak Children's Cancer Society |
| Manal Elewah | Egypt | Art2Care |
| Sawsan Abdul Salam Al Madhi | UAE | Friends of Cancer Patients |

EUROPE

| NAME | COUNTRY | ORGANIZATION |
|-------------------------------------|---------------------------------|--|
| Anita Kienesberger (chair) | Austria | Österreichische Kinder-Kreb-Hilfe |
| Luisa Basset | Spain | Fed. Española de Padres de Niños con Cáncer |
| Lejla Kameric | Bosnia & Herzegovina | Udruženje "Srce za djecu koja boluju od raka" |
| Nicole Scobie | Switzerland | Zoé4life |
| Anne Goeres | Luxembourg | Fondatioun Kriibskrank Kanner |
| Frédéric Arnold | France | UNAPECLE |
| Delphine Heenen | Belgium | KickCancer |
| Zuzana Tomášiková (Survivor) | Switzerland | Kinderkrebs Schweiz |
| Harun Šabić (Survivor) | Bosnia & Herzegovina | Udruženje "Srce za djecu koja boluju od raka" |
| Michaela Wil | Austria | Survivors Austria |
| Tiago Costa | Portugal | Acreditar |

OCEANIA

| NAME | COUNTRY | ORGANIZATION |
|--------------|-------------|--|
| Simon Lala | New Zealand | Child Cancer Foundation |
| Mary McGowan | Australia | Children's Cancer Centre Parent Advisory Committee |
| Kate Johnson | Australia | Children's Cancer Centre Parent Advisory Committee |

LATIN AMERICA

| NAME | COUNTRY | ORGANIZATION |
|----------------------------|----------------|---|
| Marcela Zubieta (chair) | Chile | Fundación Nuestros Hijos |
| Nubia Mendoza | Honduras | Fundación Hondureña para el Niño con Cáncer |
| Yolima Méndez Camacho | Colombia | Fundación Colombiana de Leucemia y Linfoma |
| Miguel de la Fuente | Perú | Fundación Peruana de Cáncer |
| Alexandra Matos de Purcell | Rep Dominicana | Fundación Amigos contra el Cáncer Infantil |

AFRICA

| NAME | COUNTRY | ORGANIZATION |
|-------------------------|----------|--------------------------|
| Daniel McKenzie (chair) | Zimbabwe | KidzCan |
| Dr John Ahenkorah | Ghana | GHAPACC |
| Brian Walusimbi | Uganda | Bless a Child Foundation |
| Sidney Misigo Chahonyo | Kenya | Hope for Cancer Kids |
| Prof Yasser Saad-Eldin | Egypt | Alexandria Group |

| | | |
|-------------------------------|---------------------|--|
| Dr Ihesinachi Kalagbor | Nigeria | Simara Children Cancer Foundation (SCCaF) |
| Nagm Azar (vice-chair) | South Africa | CHOC Childhood Cancer Foundation |
| Naïma Otmani | Morocco | Association l'Avenir |

OUR HONORARY MEMBERS

| NAME | COUNTRY |
|---|---------------------------------|
| Anita Kienesberger | Austria |
| Benson Pau | Hong Kong SAR, China |
| Gerlind Bode | Germany |
| Marianne Naafs-Wilstra | Netherlands |
| Simon Lala | New Zealand |
| Julian Cutland | South Africa |
| Sadie Cutland | South Africa |
| Christine McIver | Canada |
| Mark Chesler | United States of America |
| Gill Thaxter (for Geoff Thaxter) | United Kingdom |
| Tim Eden | United Kingdom |
| Jesús M^a González Marín | Spain |

3. Global Initiative for Childhood Cancer

EVENTS

- Strategic Spotlight on Childhood Cancer
- International Childhood Cancer Day: All hands in

(extract from WHO email)

“On February 15, 2021, the global childhood cancer community celebrates International Childhood Cancer Day (ICCD). WHO, working with UN partners and collaborators, will convene multi-sectoral representatives to launch the CureAll children with cancer technical package. This event, and this package, will support further awareness raising about the need to improve childhood cancer outcomes through the implementation of the GICC. The celebration of ICCD offers the opportunity to celebrate political commitments related to childhood cancer, to document progress in the Initiative and to catalyse stakeholders towards achieving universal health coverage and child health-related Sustainable Development Goals.”



World Health Organization

STRATEGIC SPOTLIGHT ON CHILDHOOD CANCER

HOW CAN THE WORLD GEAR UP FOR THE FIGHT AGAINST CHILDHOOD CANCER?

January 12, 2021
13:00-14:00 CET

VIRTUAL WEBINAR
JOIN US:
[HTTPS://WHO.ZOOM.US/J/96026761168](https://who.zoom.us/j/96026761168)



World Health Organization

15 FEBRUARY 2021
15.00 Geneva / 09.00 New York

INTERNATIONAL CHILDHOOD CANCER DAY

All Hands In for CureAll

Join us for the global launch of
WHO Global Initiative for Childhood Cancer Technical Package
Introduction by WHO Director-General with the participation of dignitaries and childhood cancer survivors

* Please register in advance for this webinar:
https://who.zoom.us/webinar/register/WN_HluTEPLZQSOtmJyCqwDdG

PUBLICATIONS

• CureAll Framework

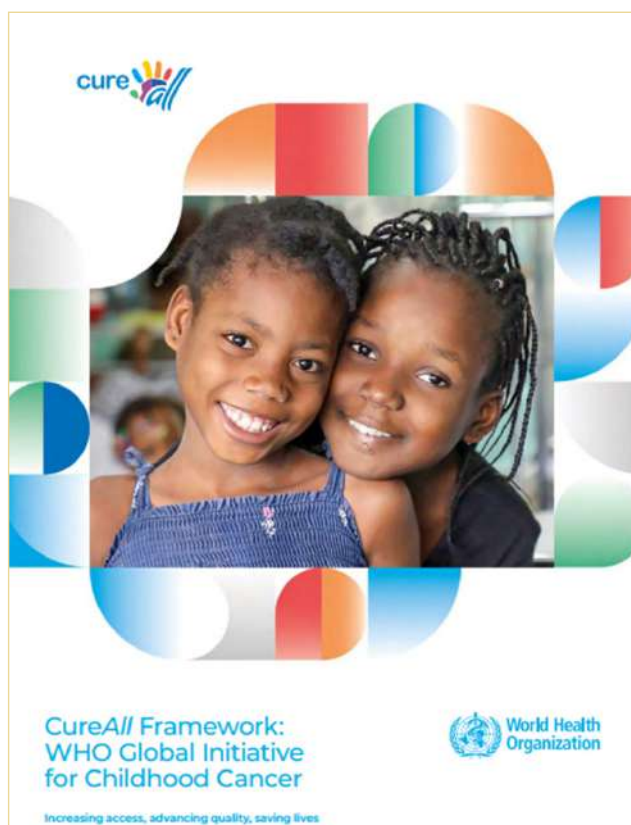
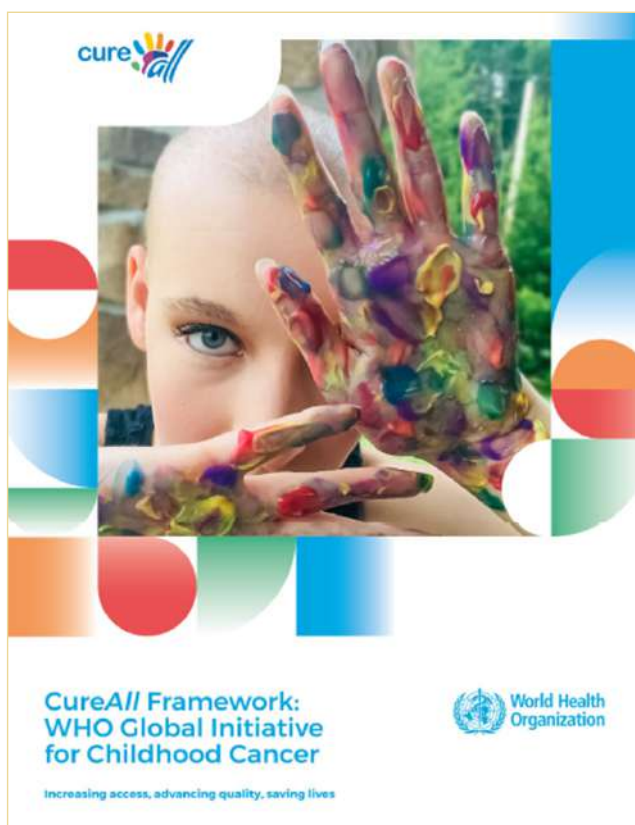
Implementation Approach. Develop models of care with referral pathways.
Strengthen training of multidisciplinary workforce.

<https://tinyurl.com/mr352hwj>

• Technical Package

This framework document is a “how-to” guide for policy-makers and programme managers to effectively implement the CureAll pillars and enablers.

<https://www.who.int/publications/i/item/9789240025271>



GICC FOCUS COUNTRIES 2021

| WHO Region RO = Regional Office | Focus Countries (Formal Ministry engagement/MoH letter of support) | Countries Participating in GICC Activities (Initial Phases including funding/no letter of designation) | Countries with Ongoing Dialogue | Regional and Sub-regional Networks |
|---|--|--|---|--|
| AFRO (RO for Africa) | Ghana Zambia Senegal | Mali Zimbabwe | Mozambique Burundi Uganda | |
| EURO (RO for Europe) | Uzbekistan Ukraine | | Georgia | |
| EMRO (RO for the Eastern Mediterranean) | Morocco | Pakistan Islamic Republic of Iran Palestine Jordan Iraq Yemen | Lebanon Libya Syria | |
| PAHO (Pan-American Health Organization Americas) | Peru Paraguay Ecuador Panamá Nicarágua Guatemala | Brazil El Salvador Dominican Republic Costa Rica Colombia | Mexico Bolivia Honduras Haití Surinam | Guyana Chile Central American and Caribbean Networks |
| SEARO (RO for South-East Asia) | Myanmar Nepal Sri Lanka Timor Leste | | Butan Bangladesh Indonesia Maldives | South-East Asia Regional Childhood Cancer Network |
| AFRO (RO for Africa) | Phillipines Mongolia Vietnam | | Laos | |

WHO - HQ INTERNATIONAL

| NAME OF CCI REPS | TYPE OF REPS | COUNTRY | CCI MEMBER ORGANISATION |
|------------------|---|----------------------|---|
| João Bragança | HQ Representative, AFRO, EURO, and PAHO Co-Focal Point | Portugal | Acreditar & CCI, President |
| Benson Pau | HQ Representative, EMRO, SEARO, and WPRO Co-Focal Point | Hong Kong SAR, China | Pau Kwong Wun Charitable Foundation & CCI, Past-President |
| Carmen Auste | HQ Representative | Philippines | Cancer Warriors Foundation & CCI, Past-President |

WHO - AFRICA (AFRO), REGION

| NAME OF CCI REPS | TYPE OF REPS | COUNTRY | CCI MEMBER ORGANISATION |
|------------------|-------------------------------------|----------|------------------------------------|
| Daniel Mckenzie | Representative, AFRO Co-Focal Point | Zimbabwe | Kidscan Zimbabwe |
| Kalizya W Zimba | Representative | Zambia | Kayula Childhood Cancer Foundation |
| Sidney Chahonyo | Representative | Kenya | Hope for Cancer Kids |

WHO - EASTERN MEDITERRANEAN (EMRO), REGION

| NAME OF CCI REPS | TYPE OF REPS | COUNTRY | CCI MEMBER ORGANISATION |
|----------------------|--|---------|--|
| Manal Elewah | Representative, EMRO Co-Focal Point | Egypt | Art2Care |
| Naima Otmani | Representative | Morocco | Association l'Avenir |
| Roula Farah | Representative | Lebanon | CHANCE Association |
| Saideh Ghods | Representative | Iran | Society to Support Children Suffering from Cancer (MAHAK) |
| Sawsan A.S. Al Madhi | Representative | UAE | Friends of Cancer Patients (FOCP) |

WHO - SOUTH EAST ASIA (SEARO), REGION

| NAME OF CCI REPS | TYPE OF REPS | COUNTRY | CCI MEMBER ORGANISATION |
|-------------------|---|------------|---|
| Poonam Bagal | Representative, SEARO Co-Focal Point | India | Cankids...Kidscan |
| Ira Soelistyo | Representative | Indonesia | Yayasan Kasih Anak Kanker Indonesia (YKAKI) |
| Krishna Sharma | Representative | Nepal | Children Cancer Foundation Nepal (CCFN) |
| Osman Gani Mansur | Representative | Bangladesh | Children Leukaemia Assistance & Support Services (CLASS) |

WHO – WEST PACIFIC (WPRO) REGION

| NAME OF CCI REPS | TYPE OF REPS | COUNTRY | CCI MEMBER ORGANISATION |
|------------------|--|-------------|---|
| Carmen Auste | Representative, WPRO Co-Focal Point | Philippines | Cancer Warriors Foundation |
| Gary Ho | Representative | Malaysia | Sarawak Children's Cancer Society (SCCS) |
| Mary McGowan | Representative | Australia | Children's Cancer Centre Parent Advisory Group (PAG) |
| Simon Lala | Representative | New Zealand | Child Cancer Foundation |

WHO - EUROPE (EURO), REGION

| NAME OF CCI REPS | TYPE OF REPS | COUNTRY | CCI MEMBER ORGANISATION |
|--------------------|--|-------------|--|
| Anita Kienesberger | Representative, EURO Co-Focal Point | Austria | Österreichische Kinder-Krebs- -Hilfe |
| Luisa Basset | Representative | Spain | Federación Española de Padres del Niños con Cáncer (F.E.P.N.C.) |
| Nicole Scobie | Representative | Switzerland | Zoé4life |

WHO - PAHO

| NAME OF CCI REPS | TYPE OF REPS | COUNTRY | CCI MEMBER ORGANISATION |
|-------------------------------|--|-----------------------|--|
| Marcela Zubieta | Representative, PAHO Co-Focal Point | Chile | Fundacion Nuestros Hijos |
| Alexandra Matos de Purcell | Representative | Dominican Republic | FACCI |
| Nubia Zuñiga | Representative | Honduras | Fundación Hondureña para el Niño con Cancer |

WHO - CARIBBEAN (CRB), PAHO SUB-REGION

| NAME OF CCI REPS | TYPE OF REPS | COUNTRY | CCI MEMBER ORGANISATION |
|-------------------------------|----------------|-----------------------|-------------------------|
| Alexandra Matos de Purcell | Representative | Dominican Republic | FACCI |

WHO - CENTRAL AMERICA (CAM), PAHO SUB-REGION

| NAME OF CCI REPS | TYPE OF REPS | COUNTRY | CCI MEMBER ORGANISATION |
|------------------|----------------|----------|--|
| Nubia Zuñiga | Representative | Honduras | Fundación Hondureña para el Niño con Cancer |

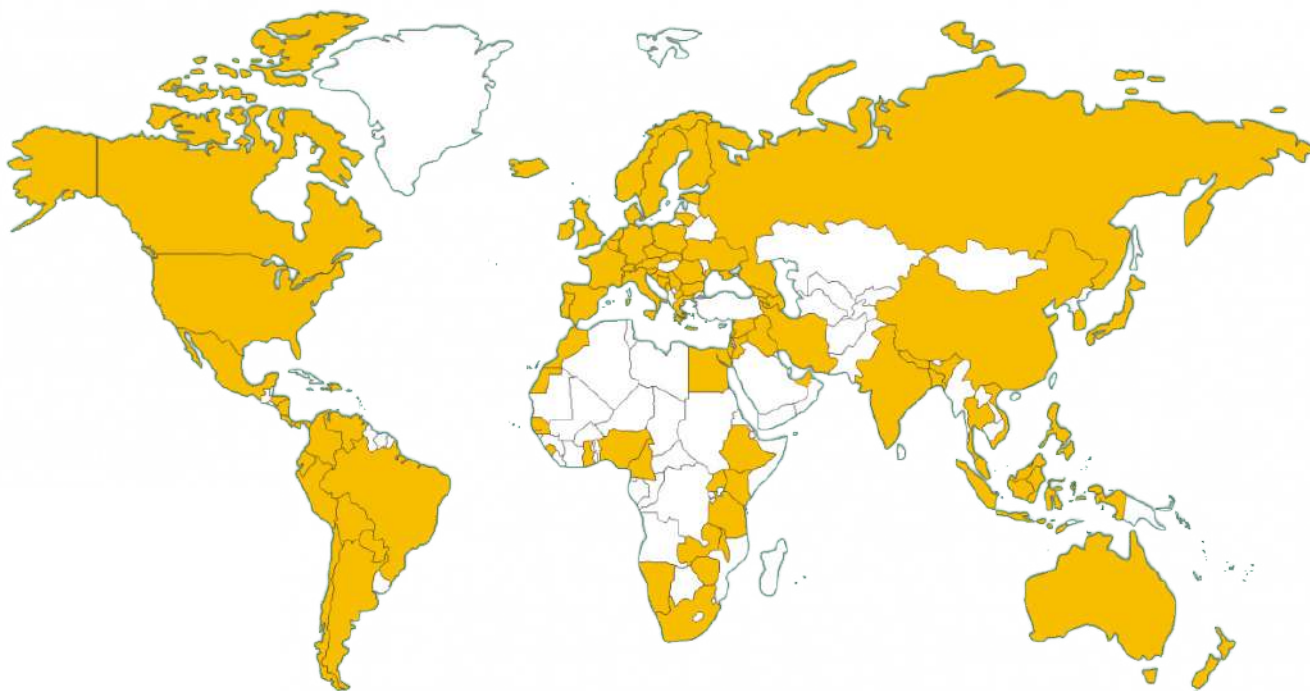
WHO - NORTH AMERICA (NAM), PAHO SUB-REGION

| NAME OF CCI REPS | TYPE OF REPS | COUNTRY | CCI MEMBER ORGANISATION |
|------------------|----------------|---------|---|
| Ruth Hoffman | Representative | USA | American Childhood Cancer Organization |

WHO - SOUTH AMERICA (SAM), PAHO SUB-REGION

| NAME OF CCI REPS | TYPE OF REPS | COUNTRY | CCI MEMBER ORGANISATION |
|---------------------|----------------|---------|-----------------------------|
| Marcela Zubieta | Representative | Chile | Fundacion Nuestros Hijos |
| Miguel de la Fuente | Representative | Peru | Fundacion Peruana de Cancer |

4. CCI Members 2021



**CCI MEMBERS: 186 ORGANISATIONS
IN 95 COUNTRIES**



26 members in 16 countries



47 members in 23 countries



67 members in 34 countries



37 members in 17 countries



5 members in 2 countries

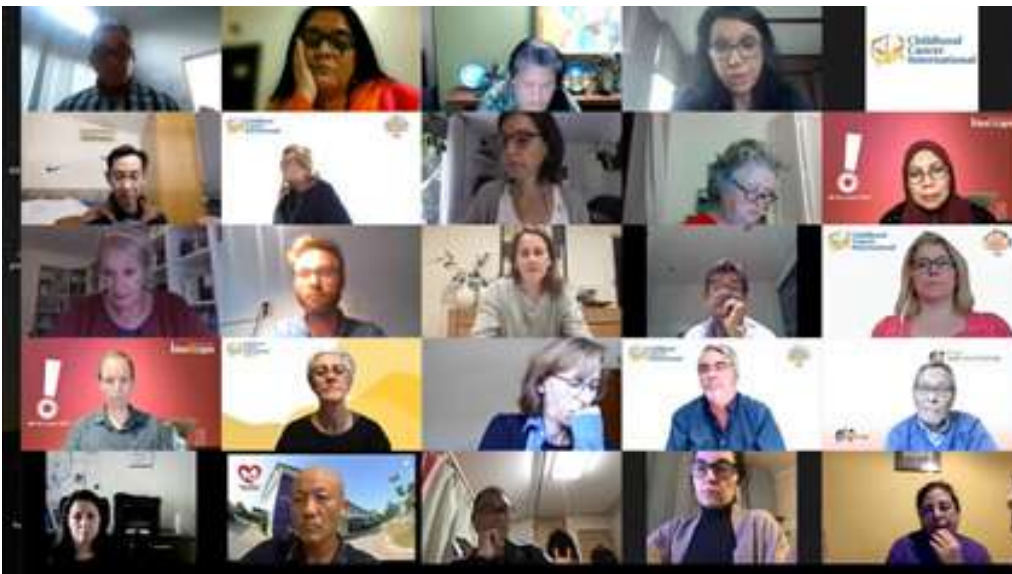


4 members in 4 countries

5. 2021 CCI Virtual Congress

Due to the COVID-19 situation around the world, it was decided that the CCI conference, scheduled to be held in Hawaii, USA, in October, should be virtual. We know that these yearly conferences have a twofold significance: the sharing of knowledge – after all, we share, we care – and the networking. In fact, these gatherings are a unique opportunity to review old friends and to meet new people.

Although we could not meet in person, we organised a very interesting programme, covering a wide range of topics, from the impact of COVID in our community to the palliative and psychosocial support, from survivorship issues to the need of building capacity and developing engagement.



For the second consecutive year, CCI held its own virtual Annual General Assembly (AGA) in keeping with our bylaws. As always, the agenda reflected the fulfilment of our statutory obligations but also the joy of sharing actions of the past and projects for the future.

The AGA was attended by more than 40 member organisations that voted the election of new Board members: Alejandra Mendez (Chile), Bindu Nair (India) and Kate Johnson (Australia). At the same time, and because they have both completed their third term in the Board, we had to say goodbye to Marcela Zubieta (Chile) and Mary McGowan (Australia). CCI is grateful to Marcela and Mary for their tireless dedication to our community.

As always, the AGA is the perfect moment in our yearly activities where we, as a community, look at the past and at the future: what have we done in the previous year? What are our objectives for the following year?

New Board Members



Alejandra Mendez (Chile)



Bindu Nair
(India)



Kate Johnson (Australia)

55

The Board of CCI, with its portfolio centred organisation, elected some area /projects as top priorities:

1. Communication
2. Fundraising
3. Internal cohesion
4. Global mapping
5. Survivors
6. Research
7. GICC, as an umbrella for everything we do.

For 2022, the Board decided to hold a bottom-up exercise, and the President had regional meetings to prepare the Action.

6. ICCD

6.1. Tree of Life Global Campaign

International Childhood Cancer Day (ICCD) is celebrated on the 15th of February each year. It was conceived in 2001 by CCI, with the first global awareness campaign in 2002.

With the rise of the COVID-19 pandemic, attention is being diverted to COVID-19 related challenges. Resources are being reallocated, and priorities are shifting. Given the global environment managing the COVID-19 pandemic in 2021, a virtual Tree of Life responsive website was being developed, and launched on the 15th of February, 2021 (ICCD).

The three-year campaign for ICCD (2021-2023) is designed to use the universal image of colourfully painted handprints of children. These handprints will represent survival rates for children with cancer on a national, regional and international scale. The roots will represent the key elements for Better Survival as follows:

1. Responsive government policy
2. Timely and accurate diagnosis
3. Effective treatment
4. Multidisciplinary care
5. Palliative & supportive care
6. Family support
7. Qualified workforce
8. Available and affordable essential medicines
9. Cancer registry
10. Rehabilitation and reintegration



• 2021 THEME: #THROUGHOURHANDS

The 2021 ICCD paid tribute to the children and adolescents with cancer, their bravery, their courage, and their resiliency; we also recognize the mark their lives have on the world and how they shape our shared future.

It was exciting to have 1553 handprints from 70 countries participated in the ICCD Tree of Life 2021 responsive website. Much appreciation goes to CCI-SIOP ICCD 2021 campaign team as well as the 109 country champions from 85 countries in helping to verify the content of messages for legitimacy and translation of the instruction for “Participate Handprints & Message” into 33 languages.

Africa Region
Zambia



Charity
Message of Hope
2021
ZACCAF enriching lives with Hope and through our hands, creating awareness, advocacy and support. We are all affected but with love, commitment and hope, we can provide the best care for our children with cancer and life-threatening blood disorders.

LATAM Region
Mexico



Silvana
Moises Mendez
2021
La mejor medicina es una buena actitud. Días malos Nunca pierdas esa sonrisa a pesar de pasar por una tormenta siempre ten un actitud positiva y lo podrás todo guerrero.

Europe Region
Russian Federation



MARTA
Message of Hope
2021
Федя желает, чтобы ни у кого не было операций, чтобы все были здоровы! Желает здоровья и силы!

Western Pacific Region
Malaysia



Ardie
Message of Hope
2021
Harapan saya agar mereka yang masih menempuh rawatan2 kimo dsb diberi kesabaran & semangat yang membara untuk terus berjuang melawan kanser.

South East Asia Region
Indonesia



SUCI
Message of Hope
2021
Saya survivor/penyintas Leukemia (kanker darah)
Semoga obat-obat Kanker selalu tersedia di rumah sakit, demi kesembuhan pasien Kanker pada Anak.
Tetap semangat dan tetap berjuang karena Kanker BISA disembuhkan.

Eastern Mediterranean Region
Iran, Islamic Rep.



Elahe Ghasemi
Message of Hope
2021
I wish you are always happy from the bottom of your heart and laugh

The Tree of Life is formed by the multi-coloured handprints of children, representing the survival rate of children with cancer in different countries.



0-20%



21-40%



41-60%



61-80%



81-100%

6.2. ICCD Highlights from around the world

AFRICA

2021 ICCD was well celebrated in Africa beginning with a Webinar hosted by WHO for the whole of Africa and attended by 503 participants. Goodwill messages came from St Jude, WHO and two First Ladies. CCI Africa members in Africa joined in the webinar but also had their own awareness programs.

The objectives of the webinar were:

- Raise awareness on issues pertinent to childhood cancer in the African Region
- Showcase best practices on management of childhood cancer
- Discuss common challenges and proffer solutions Outcomes
- Participants are aware of the issues pertinent to childhood cancer in the African region.

ASIA

ASHIC, Foundation for Childhood Cancer, Bangladesh

- On 15.02.21, ASHIC organized a program at ASHIC Shelter where Prof. Chowdhury Yakub Jamal, Dean of Faculty of Pediatrics & Medicine, Patron of ASHIC & Prof Dr. Md. Anwarul Karim, Chairman of Pediatric Hematology & Oncology, BSMMU attended.
- ASHIC participated as country champion for the Tree of Life Website. They have also taken the initiative of creating a physical Tree of Life hand prints with cancer affected children's palms.



Yayasan Kanser Kanak-Kanak (YASKA), Brunei Darussalam

Her Royal Highness Princess Fadzilah Lubabul Bolkiah, a princess of Brunei, graced the event organized by The Children's Cancer Foundation (YASKA) to commemorate the International Children Cancer Day, inked an inspiring message for children diagnose with Cancer that is placed on the Tree of Life.

The message of hope from Her Royal Highness Princess Fadzilah Lubabul Bolkiah is "Once You Have Hope, Anything is Possible". The Tree of Life located at the lobby of Women and Children Centre, RIPAS Hospital.

Guangzhou Gold-ribbon Special Children Parents Centre (GZGR), China

Play specialist Táo of GZGR hosted a physical "Tree of Life" handprint in the Pediatric Hematology and Oncology Ward in Guangdong Provincial People's Hospital to celebrate ICCD 2021. Children in the ward were having fun in putting their coloured hands on the Tree of Life. The finished art piece full of handprints of children with cancer are showcased in a public event to draw awareness. cated at the lobby of Women and Children Centre, RIPAS Hospital.

Shiyu Children Foundation, China

The "Sunflower Children" Charity Project filmed a short documentary about four parents' stories, who have children with tumors. This documentary is dedicated to all children with tumors and their families, who are brave, always sharing their messages of hopes.



(From left to right, from top to bottom)

Fig. 1 Yayasan Kanser Kanak-Kanak (YASKA), Brunei Darussalam

Fig. 2 Yayasan Kanser Kanak-Kanak (YASKA), Brunei Darussalam

Fig. 3 Shiyu Children Foundation, China

Fig. 4 GZGR Guangzhou Gold-ribbon Special Children Parents Centre

Fig. 5 GZGR Guangzhou Gold-ribbon Special Children Parents Centre

MAHAK, Iran

MAHAK planned and launched a set of online activities on the occasion of International Childhood Cancer Day 2021:

- Promoting the ICCD campaign to more than 1000 cancer-stricken children and their families as well as 3 other cancer charities in Iran (almost 150 messages registered);
- Producing 6 animations on the symptoms of the most common childhood cancers according to WHO;
- Producing a video to teach some simple and significant points about communicating with cancer-stricken children's families;
- Publishing two books of 'Chemo Hero' and 'Radiotherapy' in an online bookstores for everyone.

Korean Association for Children with Leukemia & Cancer, Republic of Korea

Promoting public interest and awareness of childhood cancer by posting advertisements in newspapers and 3 subway platform screen-door delivering ICCD 2021 key message.

Children's Cancer Foundation, Singapore

In this fourth edition of CCF's #myGOLDpledge campaign, 1,453 Singaporeans from 17 organisations and five informal groups joined CCF to pledge their support by wearing gold ribbons on International Childhood Cancer Day. One of the organisation, RSVP The Organisation of Senior Volunteers, resonated deeply with our cause and joined us in the preparation of the campaign ribbons for distribution. Besides using the gold ribbon filters, the online community also took a step further and encouraged our beneficiaries by sharing messages of hope.



Fig. 6 MAHAK, Iran



Fig. 7 Korean Association for Children with Leukemia & Cancer, Republic of Korea



Fig. 8 Children's Cancer Foundation, Singapore

EUROPE

Federación Española de Padres de Niños con Cáncer, Spain

Every year Federación Española de Padres de Niños con Cáncer) through its regional organisations invite schools across Spain to participate in the ICCD campaign. The pictures show some of the virtual Trees of Life created in many schools across the country to support children and adolescents with cancer



Fenix Crna Gora, Montenegro

Fenix Crna Gora marked February 15, the International Day of Children with Malignant Diseases in accordance with the current epidemiological situation, in a way that all television and public institutions reached an agreement on all-day wearing of the gold ribbon, a symbol of the fight against childhood cancer. In this way, the entire Montenegrin public was informed through the media about the importance of providing support to sick children and the importance of this day.



Fundación Nuestros Hijos, Chile

Chile's Health Minister, Dr. Enrique Paris, made an extensive and fruitful visit to the Oncological Rehabilitation Center of Fundación Nuestro Hijos on the International Day of Childhood Cancer. The health authority toured the facilities, spoke with patients, parents and therapists, and learned about the project for the new Foundation center.

The Minister said he was impressed with the comprehensive work our Foundation is doing to rehabilitate pediatric cancer patients and pledged government support to strengthen this work.

“They need all the support and we are going to give them all the support. The most beautiful thing of all is their work aimed at recovering children diagnosed with cancer. Many times children recover, but with physical and neurological consequences; that is the work that is done here, which is wonderful. There are stimulation rooms with music, games, a therapeutic pool, a gym, it is a gigantic job and it is necessary that many people join to collaborate with this Foundation.

CCI Latam participated in important webinars during 2021 with the aim to raise awareness about childhood cancer. For ICCD, Dr. Zubieta was invited to participate in a webinar held by PAHO to talk about the care of children with cancer during the pandemic.



Fig. 13 Dra Marcela Zubieta, President of FNH in Chile, and Dr Enrique Paris, Minister of Health from Chile

Fundación Hondureña para el Niño con Cancer, Honduras

To strengthen the roots of the Tree of Life in Honduras, the local CCI member inaugurated the re-modelling of the Ambulatory Chemotherapy Clinic at the Gabriela Alvarado Hospital. This clinic will benefit 145 patients from the Eastern Zone of the Country.

Casa de la Amistad para Niños con Cáncer I.A.P., Mexico

An activity was carried out with the supported users and their parents who were in CD-LA's shelter. Cases of supported childhood cancer survivors were screened and two survivors were invited so that they and their mothers could share their experiences, challenges, learnings and share a message of hope.

Then CDLA create a tree of life with different painting materials among all, the participants were invited to decorate the Tree of Life with something that would make them happy or remind them of their loved ones.



Fig. 14 Fundación Hondureña para el Niño con Cancer, Honduras



Fig. 15 Casa de la Amistad para Niños con Cáncer I.A.P., Mexico



Fig. 16 Casa de la Amistad para Niños con Cáncer I.A.P., Mexico

7. Survivor's Week

In June, the childhood cancer community celebrates the life of our survivors. We honour their courageous journeys and recognize the challenges they continue to face.

The journey of childhood cancer does not end after the final treatment has been given and the announcement that a child/adolescent is now cancer free. Along with the impressive gains in survival have come “late effects,” which may impair some of the survivors’ health and quality of life. Recent research reveals that as much as two thirds of childhood cancer survivors suffer long-term late effects from treatment.

Thus, Childhood Cancer Survivors need a lot of continued support and care. They and their families need assistance to proactively prepare for and successfully overcome health and other emerging challenges. They need to be well informed and well prepared to navigate the next part of their journey – the new normal and life beyond childhood cancer.

In 2021, CCI decided that the International Childhood Cancer Survivors Week (ICCSW) should be celebrated on the last full week of June. In that same year, for the first time, CCI organised a global webinar to address important issues for the survivors of today. After a first round of discussions with survivors from different parts of the world – North America, Asia, Africa, Europe, LATAM – there was an agreement on the importance of discussing mental health.

On the 26th of June, St. Jude hosted a webinar organised by CCI in collaboration with SIOP – the International Society of Paediatric Oncology – with the title “Understanding and coping with the mental and emotional impacts of childhood cancer among survivors” that was attended by hundreds of people from more than 50 countries. For the first part we invited health professional to share their research and knowledge, and in the second part we had a roundtable with 5 survivors from 4 different regions during which they shared their journey through childhood cancer but also their expectations and difficulties.

For more information on the International Childhood Cancer Survivors Week, please visit our site: <https://www.childhood-cancerinternational.org/cci-signature-events/international-childhood-cancer-survivors-week/>



8. Gold September: Highlights from around the world

During September CCI efforts were focused on raising awareness about issues that childhood cancer patients, their families, and survivors face around the globe. Our community members were encouraged to join our efforts to ensure that our voice remains strong, and we can keep the theme of childhood cancer in the spotlight.

I. Patients, survivors, families, and professionals from around the world joined in making videos to raise awareness of childhood cancer and highlight innovation, success in research, psychosocial care and survivorship. SIOF and CCI posted various themed dialogues on their website and social media per week and region:

- 1 st week: Kick-off video by CCI & SIOF Presidents
- 2 nd week: Treatment – dialogue Africa
- 3 rd week: Psycho-social – dialogue Asia
- 4 th week: Survivorship – dialogue Latin America
- 5 th week: Wrap-up

II . For the last several years, organizations around the world have built awareness of childhood cancer through the “Light It Up Gold!” campaign. Prominent buildings, national monuments, historic buildings and significant natural sites around the world have participated in this campaign by lighting them up in GOLD or by hanging huge gold ribbons in their facades. This year, we continued with this tradition and called upon our community to advocate and honor the children who are currently undergoing cancer treatment and their families. Some landmarks who joined the 2021 campaign were: BT Tower, London; The White House in the US; The Monaco’s Grimaldi Forum; The Lotus Tower in Sri Lanka and Fifty-Nine Canadian Landmarks among many others.

ASIA

• ASHIC, Foundation for Childhood Cancer (Bangladesh)

On 14 Sep, ASHIC organized a program in the ASHIC Shelter (a 20 bed of accommodation facilities near BSMMU hospital) to promote awareness amongst the admitted patients and their families. Salma Choudhury, Founder Chairperson of ASHIC precisely described the significance of this month. She requested to raise awareness about the sign, symptoms, and treatment protocol of cancer diseases of different hospitals and requested them to pass information facilities to their own neighbours. At the end of the discussion Founder Chairperson fastened the gold ribbon symbolizing the childhood cancer awareness month.

On 28 Sep, ASHIC has inaugurated their 5th ASHIC Play Centre at Department of Paediatric Surgery, Ward 13, of Shaheed Suhrawardy Medical College Hospital, at Dhaka, the Capital City of Bangladesh to commemorate the Awareness Month.



- **Indian Cancer Society (India)**

Song of Hope was released: Hope song created by Indian Cancer Society, in association with music maestro Amit Trivedi. Telling the story of a young cancer survivor. The song “Mainn Lad Lunga” seeks hope to kindle hope and strength in cancer warriors across the world.

https://www.instagram.com/tv/CUwctHjMX5/?utm_medium=copy_link

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

- **Cancer Patients Aid Association (India)**

CPAA decided to Go Gold at Mumbai’s B J Wadia Hospital by helping the children discover their inner super-powers. After a song and dance session, each child was given a golden cape. They decorated a wand with stickers and tinsel and hey presto! They could fly through the skies. The program was made possible by a generous donation from the Ashok and Sharada Sarnaik Endowment for Children Conquering Cancer. Each child was gifted a “Giving Smiles” bag packed with goodies and a gold water bottle. Hospital, Mumbai.



- **Yayasan Anyo Indonesia - YAI (Indonesia)**

28-30 Sep, YAI made a video with theme: Talk with expert about treating cancer with children and broadcasted in Rumah Anyo YouTube channel <https://www.youtube.com/watch?v=5x-LIPjhuCo>. They also gave away Rumah Anyo's mask to health workers to show their gratitude of their works in the month of September.

- **MAHAK- Society to Support Children Suffering from Cancer – (Iran)**

Buildings lit for gold: Milad Tower in Tehran; Tabiat Bridge in Tehran; Si-o-se-pol in Isfahan; Azadi Tower in Tehran; Yakhchal House in Isfahan; Jabalieh Dome in Kerman.

- **Kurdistan Save the Children (Iraq)**

19-27 Sep - Distribution of the brochure to all hospitals

- **Children's Cancer Association of Japan (Japan)**

Light up buildings in gold in various places: Tokyo Skytree, Sapporp TV (Hokkaido), Saga Medical Center Building, Three transmission towers at the summit of Mt. Inasayama (Nagasaki), Five buildings: Three Aflac Parents Houses; two in Tokyo and one in Osaka.



Fig. 17 Children's Cancer Association of Japan (Japan)



Fig. 18 Yayasan Anyo Indonesia



Fig. 19 MAHAK- Society to Support Children Suffering from Cancer – (Iran)



Fig. 20 Kurdistan Save the Children (Iraq)

• Korean Association for Children with Luekemia Cancer - KACLC (Korea)

1. Childhood Cancer Awareness Video “Shower” & SNS Cheering Comment Event:

https://www.instagram.com/tv/CTd_-ywnSum/?utm_source=ig_web_copy_linkshow

2. Childhood Cancer Awareness Cartoon & SNS Cheering Relay Event:

https://www.instagram.com/p/CT6eiN0h9KI/?utm_source=ig_web_copy_link



• Children’s Cancer Center of Lebanon - CCCL (Lebanon)

15 Sep, CCCL invited Mrs. Aline Murr (MTV Presenter and Ex Producer at Studio Visison) to spend an hour with CCCL patients to raise awareness about Childhood Cancer and the golden ribbon. Mrs. Murr visited the centre and participated with the kids in the Yoga session and the art expressive session. 23 Sep, CCCL invited Mrs. Sabine Nahass (Lebanese Ex model and a mom for a CCCL patients) to spend an hour with CCCL patients to raise awareness about Childhood Cancer and the gold ribbon. Sabine visited the centre, entertained the kids with Anthony the magician. The kids and parents enjoyed the show a lot.

• Cancer Warriors Foundation & Kythe Foundation (Philippines)

WHO Philippines and Department of Health conduct of First National Childhood Cancer Stakeholders Summit, Sep 27-29

• Cancer Warriors Foundation (Philippines)

Light UP HOPE, Light A Candle campaign launched first week September, culminating on 29 Sep. It was done virtually by posting virtual message in Facebook or by actually lighting up at 8pm. Undertaken in collaboration with network of Cancer Coalition Philippines, Healthy Philippines NCD Alliance, National Council for Disability Affairs, Philippine Association of Patient Organizations, CBM- Phil network of Persons with Disabilities, Save the Children Philippines, Phil Association of Persons with Chronic Illnesses, members of Phil Society of Pediatric Oncology, Phil Society of Oncology, Phil Society of Medical Oncology, Cervical Cancer Association of the Philippines and other professional medical societies, academic institutions, faith based groups and other civil society organizations (nationwide).

- **Kythe Foundation (Philippines)**

Light Up Hope. Light Up a Candle on 29 Sep at 8PM.



- **Children’s Cancer Foundation - CCF (Singapore)**

In addition to the light-up of iconic buildings in Singapore supported by National Gallery Singapore and KK Women’s and Children’s Hospital, Children’s Cancer Foundation (CCF) also organized an art exhibition featuring artworks done by children with cancer and their families. From paintings, to photos, to even the designing of calico whale dolls, each art piece is an embodiment of a child’s thoughts towards cancer, or an expression of their childhood cancer journey.

Local MediaCorp artiste, He Ying Ying, also championed for the childhood cancer cause and supported CCF’s campaign as a celebrity ambassador. Public supporters were invited to add a sketch of encouragement on our first-ever interactive digital canvas - sketches added in real-time formed a collective canvas of hope for children with cancer!

- **BASM Support Children with Cancer Association (Syria)**

Charity Marathon on 1 Oct as the wrap-up event for the month of childhood cancer awareness. It was a kind of walk more than a real marathon. All proceeds went to support children with cancer and BASMA association.

- **Friends of Cancer Patients (UAE)**

Light up buildings in gold in various places: House of Wisdom; Dubai Frame; Sharjah Archaeology Museum. On 14 & 28 Sep, they hosted webinars on "Know the Warning Signs of Pediatric Cancers" and "Childhood Leukaemia".



EUROPE

- **Udruženje roditelja djece oboljele od malignih bolesti "Iskra" (Bosnia & Herzegovina)**

City Administration Building and Cultural Center Banski dvor SHINE IN GOLD! Lit up with gold color in support of children suffering from malignant diseases. Distribution of promotional material and gold ribbons on Krajina Square, Banja Luka.

• Karkinaki (Greece)

Greek MEP Maria Spyraiki and the European People Party hosted an event for childhood cancer in Greece. Menia Koukougiani Co-founder and Director addressed the event. Menia Koukougiani Co-Founder and Director of KARKIKANI was interviewed by newspaper athyNEA and the article was published on 24 Sep, to promote the awareness of childhood cancer and CCAM.

<https://a8inea.com/kamia-pediki-asthenia-den-ine-tabou/>

• Federazione Italiana associazioni Genitori Oncoematologia Pediatrica - FIAGOP (Greece)

Buildings lit for gold. As part of the Campaign, on 26 September we have organized together with the associations “Image for Margo” - Kick Cancer and Fondatioun Kriibskrank Kanner a solidarity run “Io corro per Loro” to collect funds for the research.

• Association of Parents of Children with Childhood Cancer (Montenegro)

Buildings lit for gold.



• Fundacja Na Ratunek Dzieciom z Chorobą Nowotworową (Poland)

4 September - Start of the national campaign of Gold Ribbon about leukaemia: **1) Children's ultrasound examination in the park** in front of the hospital in mobile usg centre in Wrocław **2) picnic for children and parents in the park** with special events and games for children and a charity run **3) performance by a musical group and a cabaret in the auditorium hall** in the centre of Wrocław, fundraising before and after the performance II. Expert's debate about leukemia and other childhood cancers - Warsaw, 15th of September III. Rakreaton - sports challenges for companies and individuals to collect kilometres by walking, running, cycling, skating, etc - during all month of September, 8200 participants, 1 033 465 km collected, activities of fundraising during the sport challenge.

Promoted the Gold Ribbon campaign on TV, radio and press: Gazeta Wyborcza, Meloradio, Radio Rodzina, Onet Rano, TVP, TVN 24, Telemagazyn, Wrocław.pl, TuWrocław.com, Radio Gra, RMF Fm. Fundacja Na Ratunek Dzieciom z Chorobą Nowotworową did several short video about leukemia with children, and they distributed the gold ribbon pins to people.

<https://zlotawstazka.pl/fakty-i-mity/>

• Deťom s rakovinou, n. o. (Slovakia)

Deťom s rakovinou, n. o. did awareness activity for kids and parents in the kindergarten in Pezinok, Slovakia. Teachers created special day dedicated to children with cancer and invited Deťom s rakovinou, n. o. to spend a day with kids. They talked with kids about the childhood cancer and gave a gold ribbon to everyone.

Deťom s rakovinou n.o. organized an annual conference for childhood cancer survivors. They were pleased that the president of Slovakia, Zuzana Čaputová, accepted their invitation and came to have a speech and support survivors, their parents, families and doctors and nurses from Deťom s rakovinou, n. o.'s clinic.

• Federación Española de Padres de Niños con cancer (Spain)

Buildings lit for gold in various cities in Spain: Madrid/Valencia/Gran Canaria/Soria/Bilbao/Benidorm/Gijón/Granada, etc.

• Zoé4life (Switzerland)

Geneva Jet d'eau - The water jet lights up in GOLD every year to kick off this international childhood cancer awareness month. Thanks to the SIG - Services Industriels de Genève for accepting the request from Zoé4life to light up the Geneva water jet in GOLD and every year since 2013!

Day4life, a music festival to raise awareness and funds:

<https://tinyurl.com/yc3krbr8>



Fig. 21 Jet d'eau (Geneva, Switzerland)



Fig. 22 Fundacja Na Ratunek Dzieciom z Chorobą Nowotworową (Poland)



Fig. 23 Deťom s rakovinou, n. o. (Slovakia)

LATIN AMERICA

• Fundación Nuestros Hijos (Chile)

Created a video for CCI/SIOP where Dr. Marcela Zubieta, Dr. Liliana Vásquez and survivor Pablo Allard talk about the considerations that must be taken when they have talked about childhood cancer survival. FNH also promoted Childhood Cancer Awareness Month on radio.



• FANLYC (Panama)

RelevoPorLaVida, from September 1 to 22, run or walk for children with cancer in Panama. Everyone's goal is: 1,000,000 KM



9. CCI AFRICA

CCI Africa had three important highlights this year:

Successful ICCD Celebration: The event was convened by the WHO (WHO) and saw over 500 representatives from member states, official partners, childhood cancer survivors and other non-state actors participating. This was against a background of a cancer being the leading cause of death for children and adolescents around the world with 400,000 children diagnosed with cancer globally. The majority of these children live in low and middle-income countries (LMIC), where they face inequities in early detection, diagnosis, and access to quality treatment and palliative care. Key speakers at the meeting were: Dr Tedros Adhanom Ghebreyesus, (WHO Director-General), Dr Rafael Mariano Grossi, (IAEA Director-General), Dr Bente Mikkelsen, (Director, NDC), HE First Lady of Zambia, Mrs. Esther Lungu and the First Lady of Zimbabwe Mrs. A. Munangagwa.

Survivor Webinar organized by CCI and SIOP: Held on June 26th, the key focus was 'Understanding and coping with mental and emotional impacts of childhood cancer among survivors. A survivor from South Africa represented the continent.

CCI Africa Strategy : CCI Africa Regional Committee has been working on this document creating key pillars for the continent.

• CHOC CHILDHOOD CANCER FOUNDATION (South Africa)

CHOC is the anchor organisation for Childhood Cancer International in Africa and supports sister organisations in Nigeria, Mozambique, Eswatini, Lesotho, Ghana, Kenya, Zambia, Zimbabwe and others with capacity building by sharing information and knowledge.

CHOC has been in contact with Prof Naidu at BARA, the Rocking Horse Project and Phala-la Fund in Swaziland, to find solutions to the radiation problems faced at Charlotte Maxeke Johannesburg Academic Hospital. CHOC led the negotiations and found solutions so that the patients are treated without delay.

CHOC has also been in contact with Dr Bokula, a fellow from Nigeria at the Red Cross War Memorial Children's Hospital, who needed information on how to start a parent group and how to access chemo to treat the children. He was contacted with Dr. Ihesinachi Kalagbor from Nigeria for further collaboration and with Daniel McKenzie regarding the sourcing of chemotherapy in Nigeria.

CHOC worked closely with ALSAC, the fundraising and awareness organization for St. Jude Children's Research Hospital in the US. CHOC staff have completed courses given by this organisation.

CHOC Childhood Cancer Foundation celebrated its 40th birthday by publishing a book about the history of the organisation. In 2021, Carl Queiros resigned as CEO of CHOC and Hedley Lewis was appointed as the new CEO.

During the COVID-19 Pandemic, Prof Gita Naidu, President of the South African Children Study Cancer Group -SACCSG, in collaboration with CHOC, gave media statement assuring the public and cancer patients that hospitals and clinics had contingency plans to assist all patients, and infection prevention measures to prevent the spread of SARS-Coronavirus.

CHOC's awareness raising on the Early Warning Signs (EWS) of childhood cancer was of utmost importance and although CHOC couldn't do training due to physical distancing and the lockdowns, they were committed to spread the message on different social media platforms and in the media. There were stakeholder meetings with the Department of Health and had several radio interviews in the province.

• ICCD

The second Flip Flop Day was held during 2021. This annual event is a day of fun and colour because although childhood cancer is in no way lighthearted, South Africans certainly are, and when it comes to our children, we need to rally behind them.

On September the 30th CHOC held a webinar with the theme Early Detection Saves Lives. Presenters were a CHOC Donor, a Traditional Healer, A survivor and a Paediatric Oncologist. Dr Andre Ilbawi from the WHO was the keynote speaker. 170 registrations, 115 attended, 1800 watched it on Facebook live and 83 on YouTube.



• TAPCCO , Ethiopia

ICCD

Interview at EBS TV with parents, survivors, the director of TAPCCO and Dr. Abdulkadir Said. They discussed about the childhood cancer journey.

TAPCCO organized an event at Jimma, Ethiopia. Pediatric Oncology Nurses talked to parents and community members Childhood Cancer awareness event at Gondar, Ethiopia. Posters on early detection signs were printed and distributed. TAPCCO also organized lectures about the curability of cancer when treated.

• HOPE FOR CANCER KIDS (HCK), Kenya

HCK's goal is to ensure that children and adolescents diagnosed with cancer in Kenya are able to be diagnosed in good time and access comprehensive cancer treatment to increase the survival rate in line with the WHO goal to increase Global Cancer Survivorship to 60 percent. HCK is involved in creating awareness, providing financial and psychosocial support as well as advocacy. As of 2021, HCK has supported approximately 150 children and their families.

ICCD

Lions Club District 411, and Nairobi Jaffery Sports Club partnered HCK to hold an event to create a mural with handprints symbolizing the work done towards supporting childhood cancer patients and highlighting the impact left in the participants' lives. Lions Club's in Kenya made a donation to support 120 children for an entire year. Such partnerships have allowed HCK to make substantial gains towards reducing the financial burden on families and providing access to comprehensive cancer treatment.

MEDICAL CAMP AT URAFIKI MEDICAL CENTRE

On July, HCK was invited to raise awareness about childhood and breast cancer at a free medical camp at Urafiki Medical Centre. About 500 people were educated on these cancer types.

CHILDHOOD CANCER AWARENESS MONTH

On September we held a fundraising and awareness walk. The event was a success with Kenya based Lions Clubs raising over KES 500,000 towards supporting upcoming pediatric oncology units and the children they care for.

KENYATTA NATIONAL HOSPITAL DONATION

HCK and its partners donated 60 care packages to children and caregivers at Kenyatta National Hospital, who usually come from low income backgrounds.

LONG TERM PLANS

One of the long-term plans at HCK is to reduce treatment abandonment by tackling the challenges faced by families with a child facing cancer. HCK hopes to open accommodation centers where the children and families can stay when they need to relocate to receive treatment.

• KIDZCAN (Zimbabwe)

Operations were buoyed by a robust set of activities with events created around need areas. The Mudrun is one such event that kicks off the year followed by the Orange Month with strong participation of top schools, where students wore orange clothes and contributed with a dollar or more. Paediatric Cancer Early Detection and Awareness Campaigns were held in the country Kidzcan continued to provide families and patients with psychosocial support and services including clinical care, advocacy, and case management. They also offer Chemotherapy drugs, CT and MRI Scans and transport allowances. They also source and provide prosthetics, admission, and discharge packs. Children also receive play and learning materials. All these are provided free of charge.

It is this holistic approach that has cut KidzCan Zimbabwe's place on the top echelons of the Zimbabwean public health system.



10. CCI ASIA

ADVOCACY AND AWARENESS CAMPAIGNS

• Lebanon - Children's Cancer Center of Lebanon (CCCL): London Global Cancer Week

In November 2021, CCCL organized a session in London Global Cancer Week hosting leading advocates for cancer institutions such as the WHO, SIOP Europe, UNGCL and Oncologists from Lebanon and audience from all over the world. The virtual conference lead by the CCCL General Manager, Mrs. Hana Chaar Choueib, discussed the "Non-Profits' Role in Cultivating Cross Regional Relationships for Cancer Control".



• Japan – Children's Cancer Association of Japan (CAAJ)

Prior to the publication of the 4 th Cancer Control Basic Program by the government in 2023, CCAJ has set up a working group consisting of 20 parents and 15 survivors of childhood cancer to present petitions to the government for children as well as adolescents and young adults with cancer to bring about improvements of their quality of life reflecting

their voices in the Program. The petitions were handed over to the government officials concerned of the Ministry of Health, Labor and Welfare as well as the Ministry of Education by the members of the working group.

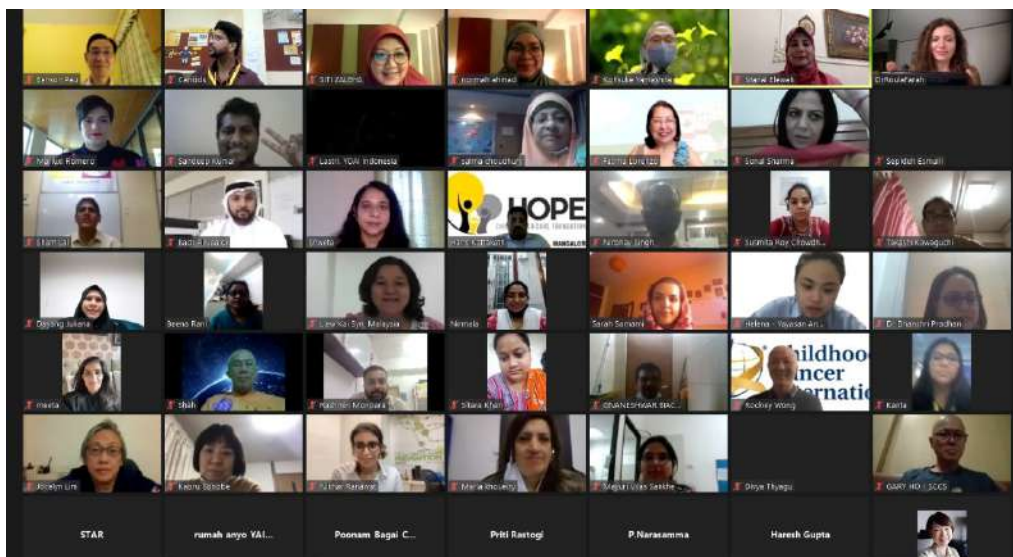


EVENTS

• The 13th CCI Asia Conference

Due to the unexpected global pandemic, the 13th CCI Asia Conference to be held in Mumbai, India in 2020 was cancelled. However, with great effort from local organizer, Cankids... Kidscan, and the CCI Asia Conference Team, the first ever CCI Asia virtual conference was successfully held on 21st & 22nd March, 2021. More than 80 participants representing 30 Childhood Cancer Organizations from 12 countries (Bangladesh, China, India, Indonesia, Iran, Iraq, Japan, Lebanon, Malaysia, Nepal, Philippines, and the UAE) attended the virtual conference.

We had a session on WHO Global initiative for Childhood Cancer (GICC) plan and forward action. The representative from the South-East Asia Region, Dr Gampo Dorji and Dr Anne Akullo from the Eastern Mediterranean Region participated in this session.



• Asia Pacific Patient Innovation Summit

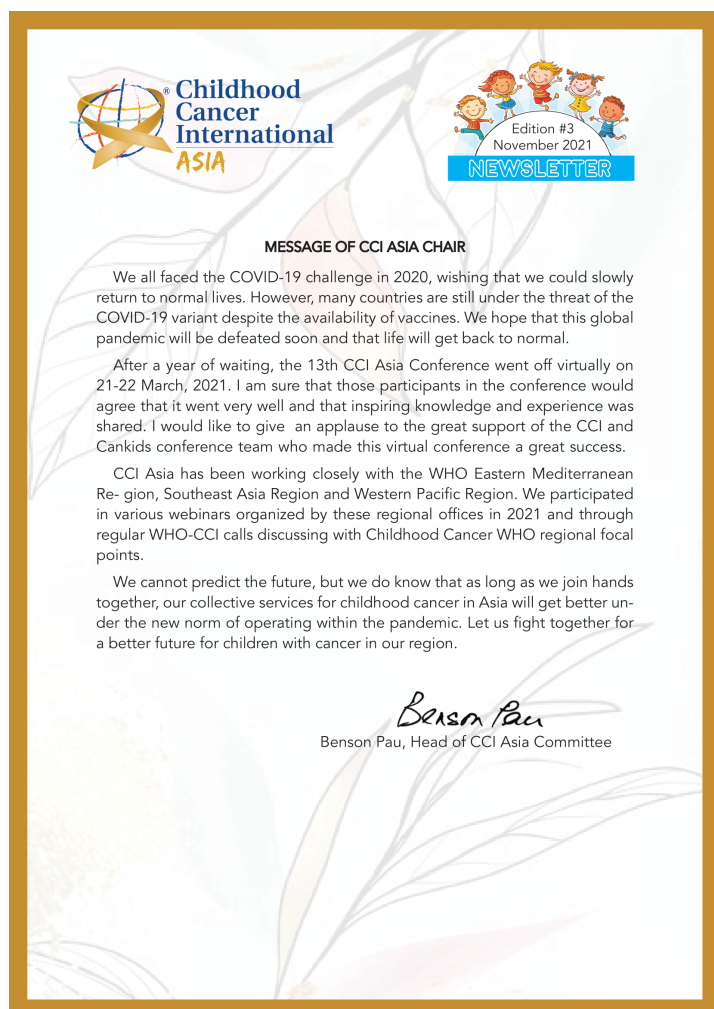
Cancer Warriors Philippines CEO, Carmen Auste, was a key presenter in the 2021 Asia Pacific Patient Innovation Summit (APPIS) in May. She discussed the role of patient support groups in clinical trials and health research and what they can do to better inform patients of their rights and the benefits/risks of participating in clinical trials and health research.

• World Congress of Gynecology and Obstetrics

For the World Congress of Gynecology and Obstetrics, sponsored by FIGO (International Federation of Gynecology and Obstetrics), Cancer Warriors Philippines CEO, Carmen Auste, discussed Engaging and Mobilizing Local Stakeholders in Promoting, Supporting and Sustaining Project SUCCESS (Scaling Up Cervical Cancer Elimination Through Secondary Strategies). HPV Vaccination of 10-14-year-olds (girls and/or boys) is a major prevention strategy that helps protect them from developing HPV or in the case of girls, cervical cancer.

PUBLICATIONS

Edition 3 of CCI Asia Newsletter were published in November 2021



PARTNERSHIP

• Cancer Warriors Foundation, Philippines, and Union for International Cancer Control

Cancer Warriors Foundation, as a country champion of the Union for International Cancer Control (UICC), collaborates with Expertise France, JHPIEGO USA, and JHPIEGO Country office in the implementation and localization of the SUCCESS Project. Carmen also led an online learning session for the Union for International Cancer Control (UICC) Master Course on Sustainable Financing for Cancer. These had participants from various regions of the world.

PARTNERSHIP - WHO REGIONAL OFFICES

• CCI Asia participated in the following WHO regional activities

CCI Asia had been working closely with the WHO Eastern Mediterranean Region, South-east Asia Region and Western Pacific Region. We participated in various webinars organized by these regional offices in 2021 and through regular WHO-CCI calls and discussed with Childhood Cancer WHO regional focal points and representatives in these regions.

• Eastern Mediterranean Region

25-26 January - Regional virtual consultation meeting on the Global Initiative on Childhood Cancer (GICC).

25 February - Dialogue with experts from CureAll children in the Eastern Mediterranean Region

22 April - EMRO called for GICC project proposals to support. Six out of forty entries finally selected, four of EMR CCI country members also submitted but not successfully selected. Three Asia Regional Committees, Benson Pau, Manale Elewah, and Sawsam Al Madhi were invited as Project Reviewers.



- **Western Pacific Region**

Participated in Second WHO Western Pacific Region Partners' Forum on 30 June – 2 July.



11. CCI Europe

2021 was the first year of CCI Europe being officially registered as a branch of CCI. We are proud to present our work and achievements.

ADVOCACY AND AWARENESS CAMPAIGNS

- **International Childhood Cancer Awareness Day**

15 th February 2021

CCI Europe, Society for Paediatric Oncology (SIOPE) and PanCare marked International Childhood Cancer Awareness Day through an event that was this year hosted by childhood cancer supporter Member of the European Parliament (MEP) Loucas Furlas in the EU Parliament. The European childhood cancer community welcomed the launch of “Europe’s Beating Cancer Plan” on this ICCD event, marking the beginning of a new era in cancer prevention and care, and putting childhood cancer under the spotlight in the EU. CCI Europe Committee members, Lejla Kamerić and Delphine Heenen had the chance to give inspirational speeches, where the need of an equal access to medicine was highlighted, as well as an importance of advancing research.

- **Childhood Cancer Survivors Week 2021**

Last week of June

Childhood Cancer Survivors Week is a week to raise awareness on challenges survivors go through and advocate for improving the quality of life after cancer. In this week, survivors spoke up about mental health issues during life after cancer, and the rest of the world listened. The campaign was proven successful, as many survivors across Europe engaged with their own experiences, and realized they are not the only ones going through these challenges.

- **Childhood Cancer Awareness Month 2021**

September

In the Childhood Cancer Awareness Month 2021, CCI Europe dedicated one week to each of our pillars and topics we are working on:

1. **Research and Innovation**
2. **Diagnosis, Treatment and Care**
3. **Psychosocial Care**
4. **Survivorship**

Goal of presenting one topic per week was to show the world we are working on practical solutions to solve childhood cancer issues around Europe.

The final week was devoted to talking about European Policy and advocacy possibilities on the European level, followed by a webinar organized by SIOPE Europe in partnership with CCI Europe, named Special SIOPE-MAC Webinar for Gold September: Childhood Cancer Awareness Month:

“Towards a Transformational Change for Children and Adolescents with Cancer in Europe: Synergies between Europe’s Beating Cancer Plan and EU Cancer Research Programmes”.

The webinar was hosted by childhood cancer supporter MEP Véronique Trillet-Lenoir.



EVENTS (MEETINGS, WEBINARS)

• CCI Europe Conference 2021

CCI Europe Conference 2021 was held virtually in partnership with SIOPE. This provided us with the excellent opportunity to gain information and have an impact in the field of research and development, discuss with medical experts about various topics, create joint sessions with health care professionals and hold plenary sessions with multiple stakeholders. Like every year, the CCI Europe Conference gave the voice to parents, patients and survivors the chance to exchange experiences, as well as provide support and information to the community.

• Webinars on Public Consultations

Throughout the year, the European Commission launched public consultations on topics that have a great impact on our community. Those relevant for the childhood cancer world in Europe were concerning Cross-Border Health, European Health Data Space, Paediatric Medicines and Orphan Drugs Regulations and General Pharmaceutical Legislation.

CCI Europe held a webinar before each public consultation in order to prepare our members for participating in them, to provide toolkits and give crash courses on how to navigate the platform. These webinars have proven efficient, as we mobilized our members to participate in the consultation resulting in the childhood cancer community being one of the most responsive groups in these consultations.

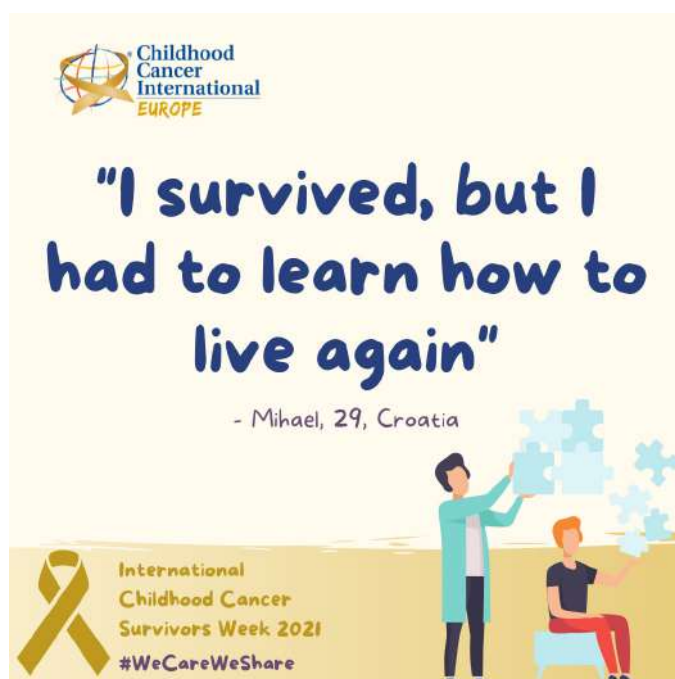
• ICCD Webinar

Currently in its 11th edition, the ICCD is an annual flagship event to mark the International Childhood Cancer Awareness Day (15 February). Organized virtually this year, it regularly gathers a large multi-stakeholder audience with interest in childhood cancer and related issues on the health and research agenda. All individually rare, paediatric cancers jointly represent the first cause of death by disease in children older than 1 year in Europe: more than 6,000 young patients die, and 35,000 cases are diagnosed annually. While substantial improvements have been achieved, there has been little progress in the cure rate of several paediatric malignancies, which are still driving mortality today.

The rarity of individual paediatric cancer types and their leading collective health burden across Europe make coordinated EU level approaches crucial. The ICCD event is thus dedicated to finding novel solutions to foster progress in childhood cancers through EU policy, programmes and collaboration with all stakeholders.

• Gold September Webinar

Each Childhood Cancer Awareness Month is topped off with the Gold Webinar in the end of the month. This year's webinar focused on maximizing the impact of childhood cancer actions outlined in Europe's Beating Cancer Plan and highlighting the importance of a synergistic approach with EU research programmed to achieve a transformational change for these young patients.



PUBLICATIONS

• Who wouldn't want to cure 100% of childhood cancers?

More than eight in ten children and adolescents in Europe diagnosed with cancer now survive their disease. But the serious life-long damage that is inflicted by many treatments is still too often a taboo subject. CCI Europe representatives want to see more openness and higher priority given to ensuring all survivors get the support they need. Read the article in Cancer World here:

<https://ccieurope.eu/download/who-wouldnt-want-to-cure-100-of-childhood-cancers/>

• Surviving childhood cancer: how we standardise care across Europe

Treatment of childhood cancer is not equal within Europe – and this inequality leaves tangible marks. The most recent study of childhood cancer survival across Europe showed that survival was generally lowest in Eastern Europe, where the survival rate for paediatric cancer was between 10 and 20% lower than in Western Europe. And for cancers with poor outcomes, such as AML or osteosarcomas, these disparities became even larger. Lejla Kamerić, CCI Europe Committee Member, talks about inequalities in Europe for Cancer World:

<https://cancerworld.net/surviving-childhood-cancer-how-we-standardise-care-across-europe/>

• Europe's Beating Cancer Plan

The European childhood cancer community is delighted that childhood cancer is now under the spotlight in the EU Cancer Plan. Our community including paediatric haemato-oncologists, parents, patients and survivors, is now looking forward to shaping the implementation of these proposals building on existing projects and structures in the community.

<https://ccieurope.eu/download/europes-beating-cancer-plan/>

PARTNERSHIPS/COUNTRY CONNECTION/COLLABORATION

In order to ensure the best possible care for children, adolescents and young adults with cancer, we are in partnership with several European organisations:

SIOP Europe is the only pan-European organisation representing all professionals working in paediatric oncology. CCI Europe and SIOP Europe have established a formal agreement of cooperation (MoU – Memorandum of Understanding) in the areas of Research and Development, access to standards of care and expertise, social sciences and ethics and the improvements to the regulatory and political environment at pan-European and national level.

PanCare is a multidisciplinary pan European network of professionals, survivors and their families that aims to reduce the frequency, severity and impact of late side effects of the treatment of children and adolescents with cancer. CCI Europe is working with PanCare in the area of survivorship care, including two major EU projects: PanCareFollowUp & PanCareSurPass.

European Cancer Organisation aims to reduce the burden of cancer, improve outcomes and the quality of care for cancer patients, through multidisciplinary and multiprofessionalism. As the not-for-profit federation of member organisations working in cancer at a European level, the European Cancer Organisation convenes oncology professionals and patients to agree policy, advocate for positive change and speak up for the European cancer community. CCI Europe is representing the paediatric parents' and survivors' interest through its participation in the European Cancer Organisation's Patient Advisory Committee (PAC).

EURORDIS is a non-profit alliance of 851 rare disease patient organisations from 70 countries to strengthen the patient voice and shaping research, policies and patient services of rare diseases. CCI Europe is collaborating with EURORDIS especially within the European Reference Networks (ERNs) and the Joint Action on Rare Cancers (JARC).

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

CCI Europe is actively involved in **ACCELERATE**, a multi-stakeholder platform created from an EU-funded project (ENCCA) aiming to efficiently improve development of new anticancer drugs for the paediatric population at European and global level. ACCELERATE have been described in "Creating a unique, multi-stakeholder Paediatric Oncology Platform to improve drug development for children and adolescents with cancer":

- **To accelerate science driven development of paediatric oncology drugs.**
- **To facilitate international cooperation and collaboration between all stakeholders.**
- **To improve early access to new anticancer drugs in development for children and adolescents.**
- **To set-up long-term follow-up (LTFU) of children and adolescents exposed to new drugs.**

RESEARCH

As one of 5 main topics that CCI Europe is working on (Diagnosis, Treatment & Care, Psychosocial Care, Survivorship, Capacity Development), research is covered by our Research & Innovation pillar.

The pillar was created because there is an urgent need for efficacious, less toxic and innovative medication and treatments to improve the cure rate and reduce the long-term side effects are needed in Europe. A multidisciplinary approach between all stakeholders is a way to achieve progress and ensure proper care with an adjusted regulatory environment.

CCI Europe's Research & Innovation Pillar gives aims to contribute in the development of novel and better diagnostic and treatment tools in the childhood cancer area. This pillar's working group members ensure that patient advocates are present and actively involved along the whole continuum of research and development. Discovering the causes of paediatric cancer, ensuring access to innovation and better treatments, improving regulatory environment and securing best possible quality of life.

CCI EUROPE DEFINED 4 SUB-PILLARS WITHIN THE RESEARCH AND INNOVATION PILLAR:

- 1. Clinical Trials:** Involvement of patient advocates in the design of clinical trials from the early stage, in order ensure a patient-centred approach.
- 2. New Therapies and Treatments:** Involvement of patient advocates in novel and safer treatments with less side-effects and long-term sequelae, tailored to patient-centred approach.
- 3. Regulations:** Involvement of patient advocates in order to ensure sufficient legislations across all Europe, e.g. revision of EU Orphan and Paediatric Medicine Regulations. Such EU regulatory initiatives should encourage better drug development for life-threatening paediatric diseases.
- 4. AYA – Adolescents and Young Adults:** Better involvement and participation of AYA patients in research of possible treatments is immensely needed.

Some of the research projects CCI Europe is involved in are:

PanCareFollowUp (PCFU) Project: Aims to improve the quality of life for survivors of childhood cancer by bringing evidence-based, person-centred care to clinical practice in the real world. CCI Europe is responsible for knowledge sharing and dissemination within the PCFU. Furthermore, the Survivorship Pillar of CCI Europe is involved in all tasks and developments throughout the project lifetime.

UNICA4EU: An EU funded project where CCI Europe participated in writing the proposal in 2021. UNICA4EU's vision is to pave the foundation of the ecosystem that will facilitate the upscaling and wide-scale application of Artificial Intelligence to Paediatric Cancer in the next ten years. The project kick-off is in 2022 and you can hear all about it in the next Annual Report.



12. CCI LATAM

2021 REGIONAL ACHIEVEMENTS

• Advocacy and Awareness Campaigns

Latam network also held campaigns in aim to create conscious in awareness and to make advocacy for a few important issues that affect the treatment or response of childhood cancer in their countries.

In Ecuador, APNACC provided support for lack of medicines and supplies in public hospitals in their country talking about this situation in press and with authorities searching for actions and solutions that could aloud treatment of cancer in all ages. Thanks to the support of APNACC and other organizations some supplies were provided to hospitals.

In Brazil, CONIACC a non-profit umbrella organization which represents 47 member organizations organized monthly lectures such as the information about a new law that could affect the telemarketing of entities (LGPD – General Data Protection Law), presentation of CCI to which CONIACC joined in March 2021, St. Jude workshop, Bayer Webinar, and several others. Also, they held the “Forum de Dirigentes” a forum addressed to the directors of our associated entities, which takes place every 2 years.

CONIACC's major initiative “Campanha Setembro Dourado” (Golden September Campaign) is known as the Childhood Cancer Awareness Month and is recognized by the Brazilian Ministry of Health as part of the national health agenda. In 2021, to celebrate that event, CONIACC promoted several lectures with important guests, among them Mr. João Bragança, CCI President, and Dr. Liliana Vasquez, PAHO.

In Peru, Fundación Peruana de Cancer held a program called “Ambassadors of Health” which was created as a complement to the Foundation’s “Prevention of Cancer” pillar. This It is a network made up of prestigious medical oncologists who join the efforts of the FPC with the aim of preventing and detecting the disease in time and thus contributing to the reduction of cancer morbidity and mortality in the country.



“APNACC”
ASOCIACIÓN DE PADRES DE NIÑOS Y ADOLESCENTES CON CÁNCER

• Events (meetings, webinars)

During the 2021, and because of the pandemic, CCI Latam held the annual conference online. This instance was made from May 18 to May 19 and had the goal to present the newest information related to CCI Global and CCI Latam, also with news about the development and advances of the implementation of GICC in Perú. This event count with the presence of Dr. Marcela Zubieta (CCI Latam), João Bragança, Luisa Basset (CCI Global) and Liliana Vásquez (PAHO) and with all the CCI Latam network. 110 people from 37 organizations from 14 countries attended this virtual event.

For its part, Brazil held the 6th forum on pediatric oncology, which was attended by Dr. Zubieta.

For its part, Mexico held the II national meeting of NGOs to help children and adolescents with cancer in the country were CCI Latam had presence.



• Publications

Members of the region had the chance apply to publish articles in Cancer Report for the special issue “Patient-led Research and Advocacy Efforts”.

From Ecuador, members of APNACC wrote “The impact of our fight” to tell the story about their work in that country. From Chile Fundación Nuestros Hijos had the opportunity to publish 3 articles which had the objective to present different work experiences from the Foundation through the pandemic. The articles were “Securing continuation of treatment for children with cancer in times of social unrest and pandemic”, “Public-private collaboration in the provision of palliative care for children and adolescents with cancer: A Chilean experience” and “Holistic rehabilitation for children with cancer: The Chilean model”.

• Partnerships. Country Connection/Collaboration

A. SLAOP

In 2021 we entered into a collaboration agreement with SLAOP, formalizing the joint work that both organizations do in Latin America on issues related to childhood cancer.

Dr. Marcela Zubieta participated in the XXXII Latin American Congress of Pediatric Oncology making a presentation of the work of CCI and CCI Latam.

B. ENLACE

Fundación Nuestros Hijos (Chile) in alliance with the Chilean Agency for International Cooperation for Development, implemented a program called ENLACE that had the goal of improve the capacity of the NGO related to childhood cancer in Latin America. This program has 2 phases and during 2021 the first phase was carried out with the participation of 14 CCI Latam member organization from 10 countries. This stage evaluated and qualified the level of organizational development based on the following aspects: Strategy, Management, Information Management, Institutional Image, Legal, Administration and Programs in order to generate sustainability and sustainability. During 2022 the second phase will be developed.

PERSPECTIVAS DEL CÁNCER INFANTIL EN AMÉRICA LATINA
14 Octubre 2 PM
Detección Temprana, Trabajo Interdisciplinario y Políticas Públicas para el abordaje del Cáncer Pediátrico en la región.

Argentina
Edith Grynspancholic
Presidenta Fundación Natali, Ombú Flemer de Argentina
Co-Fundadora del Comité Psicosocial SLAOP

Chile
Marcela Zubieta
Presidenta de la Fundación Nuestros Hijos de Chile
Miembro Board Childhood Cancer International

Jueves 14 de octubre
2 p.m.
4 p.m.
Conéctate: www.facebook.com/SanarCancer
Organiza: Fundación Sanar

XXXII CONGRESO LATINOAMERICANO DE ONCOLOGÍA PEDIÁTRICA
(en homenaje al Dr. Arturo Moreno)
SLAOP

Organizaciones de Ayuda - Childhood Cancer International (CCI Latam)
Jueves 18 de Noviembre 15-20h ARG

Oradores:

- Liliana Vásquez (Perú)
- Edith Grynspancholic (Argentina)
- Marcela Zubieta (Chile)
- Andrés Portillo (Colombia)
- Viviana Trigo (Perú)
- Juan Quintana (Chile)
- Teresa Fonseca (Brasil)
- Andrea Vargas (Chile)
- Miguel de la Fuente (Perú)
- Carlos Fries (México)

Moderadores:
• Dra. Victoria Sobrero • Dra. Marcela Zubieta

Inscríbete en: <https://bit.ly/3j8yekp>
congreso virtual SLAOP 2021

- **Miscellaneous**

During 2021 the survivor group “Faros de Vida” was founded and they focused their work on the incorporation of members from different countries in Latin America. They held an integration event that had 62 participants and to get to know the network they applied a survey where 55 survivors participated.

They also incorporated 2 new representatives of LATAM from Venezuela and Uruguay and participated as guests in different instances: XXXII Latinamerican Congress of Pediatric Oncology (SLAOP), the 2nd encounter of NGO that support childhood cancer in Mexico and Spain Federation of Childhood Cancer Parents. Sindery Rincon was at the first encounter of survivors in Venezuela and Carlos Frías was at the 2021 CCI’s Survivors Webinar participating as a panelist and assisted to the 7th virtual encounter to childhood cancer control moderated by OICI.

They are continuing their job expanding the network trough Latin America and including more survivors into their activities so that way more voices can be heard.



- **Members**

The CCI Annual General Assembly approved the incorporation of two organizations from Brazil as CCI members: Beaba Foundation and the Confederation of Childhood Cancer Organizations in Brazil (CONNIAC). To seeking new members in the countries we will be naming representatives in each LATAM country so that way we will get the chance to know more closely the work of our network and will be able to reach more organizations.

13. CCI Oceania

Childhood cancer in the Oceania region suffered more than many other world regions because of our extremely long lockdowns. Not only were our lockdowns different between New Zealand and Australia but also between the different States and Territories within Australia.

We did have one virtual parent meeting in June 2021 with 50 parents in attendance. Topics covered roundtable type virtual presentations from an ex patient - dealing with on going side effects, an insight from a teenage sibling of the impact of her brothers diagnosis on herself and her family and these two presentations were very well complimented by a presentation from a grandparent of the impact of her grandsons diagnosis not only on his parents and siblings but the impact on the extended family. These personal stories were greatly received by the attendees as was a presentation from a neuropsychologist on “Dealing with the everyday issues facing the paediatric oncology family including caring for the caregivers”.

Childhood cancer groups in our region run on a different format to that of the other regions of CCI. The medical care in all these countries are also extremely different. Over the past year both CCI and SIOP board members have commenced discussions to engage with our peers in Papua New Guinea and improve outcomes for patients and families in PNG diagnosed this year and in the future. The New Zealand members are very proud to say that their hard work over the past few years with parents and treating teams in Fiji is definitely coming to a peak with the employment of an outreach nurse to assist Fijian families. We have had several meetings to provide support and aid to a parent in Papua New Guinea who is keen to establish their first parent support group.

With enormous shoes to fill, Kate Johnson recently took over from Mary McGowan as the Oceanic Trustee on the CCI Board. With the borders now opened, there is much enthusiasm to restart the support programs that were implemented prior to the pandemic as well as more regular meeting for the Oceania regional committee.

We are very proud that our Mary McGowan was recently awarded an Order of Australia recognising her phenomenal work in nursing and charity work with Paediatric. Oncology. In addition, it was announced that she would also be inaugural life member of ANZCHOG.



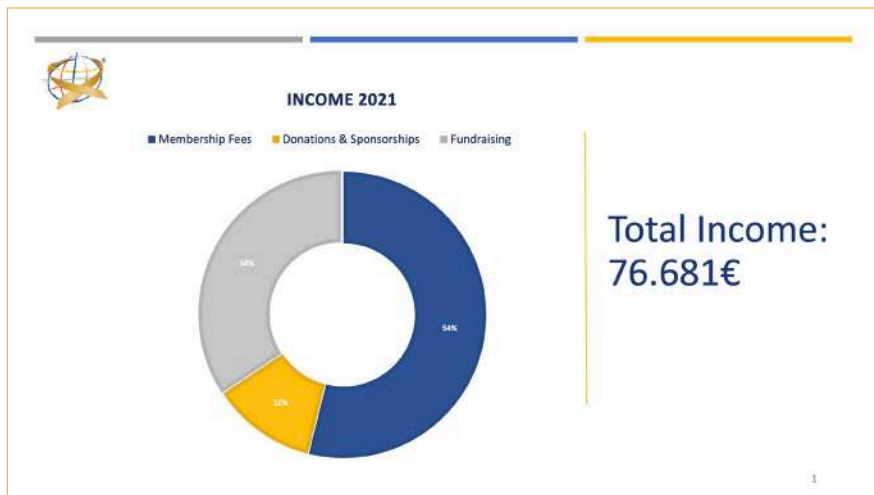
14. Financial Statement

The two graphs below provide a general idea of the state of our finances for the year ended the 31 st of December 2021.

Regarding the Income, the Membership Fees represent slightly more than 41.000€, versus 39.000€ in the previous year. During 2021 CCI fundraised around 26.000€, and Donations & Sponsorships represent 9.000€.

As for the Costs, it should be highlighted that the Program Costs represent approx. 35.000€.

Financial Statements Income and Costs



For the complete financial reports click here:

<https://www.childhoodcancerinternational.org/about-cci/our-impact>



LEARN MORE ABOUT US

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