



# ANNUAL REPORT 2022





# CONTENTS

01. Message from the President
02. Board of Trustees
03. Regional Committees
04. CCI Members 2022
05. 2022 CCI Global Annual Conference  
Barcelona
06. Regional Conferences and Knowledge Sharing
07. Global Campaigns and Awareness
08. Strengthening the Movement  
Capacity Development
09. Survivors
10. Networking and Partnerships
11. Special Projects and Member Projects
12. Communications and Social Media
13. Financial Review



# 01.

## Message from the President

Whoever among us has learned through personal experience what pain and anxiety really are must help to ensure that those out there who are in physical need obtain the same help that once came to him. He no longer belongs to himself alone; he has become the brother of all who suffer. It is this “brotherhood of those who bear the mark of pain” that demands humane medical services.

Albert Schweitzer

I have said repeatedly: an Annual Report does not reflect everything we do, or how we do it. A distracted eye sees events, people, drawings, races, official moments, prize giving ceremonies. A closer look imagines the dedication, commitment, and effort. We know, however, that **what is essential is invisible to the eye**. And the essential thing is this brotherhood that Albert Schweitzer spoke of. A brotherhood founded and sustained by those who bear the mark of pain, because they have had the experience of hearing “your child has cancer, because they have experienced the anguish of saying goodbye to a child or the joy of seeing a child cured. A wise look guesses this brotherhood that cannot be seen. That is also what the Annual Report is about: **a brotherhood of those who bear the mark of pain**.

One of the great motivations for the existence of the CCI, as a global organisation, is the fight against inequalities. Apart from being divided into sections or regions, an Annual Report must be read considering this global intention. Only a vision with equal attention to all regions, all countries, all organisations, will allow us to see this joint action, this permanent fight against inequalities is a fight against the current rule that states the greatest factor for the survival of a child with cancer is the place where he or she happens to live.

In the last two years I chose for the cover picture a child I knew: she was diagnosed just before turning one, and is now in good health, thanks to the doctors' competence, her inner strength, and the endless love of her parents. The photography we chose for this year must be seen as a reality – as it was in previous years – but also as a metaphor. All those people exist, they have a name, an identification card, a country of origin. They heard the diagnoses or accompanied someone who had been diagnosed. This is the tangible – humanly tangible – part of that mosaic of photographs.

There is, however, a subtle metaphor in that mosaic of faces, hugs, smiles or certainties of suffering. All those people are protagonists of the same story made of suffering and hope in unfair proportions. Those people – adults, children, mothers, siblings, survivors – represent our **diversity**, the inhabitants of a common global home that extends to every corner of the Earth. Behind a physiognomy that identifies an age or a geographic region there is a story that has no colour, religion, politics, or sex. A universal story whose invisible thread connects us all, this brotherhood of those who bear the mark of pain.

The WHO Global Initiative for Childhood Cancer – it cannot be repeated enough – is the great project of our times. Perhaps for the first time ever, the most important stakeholders – WHO, CCI, SIOP, St. Jude’s, others – are united in a common strategy. Before we were united by a common **purpose** – to improve the living conditions of patients, survivors, and their families – we are now united by a common **strategy**, based on objectives, plans, actions and results. There is an indomitable will to achieve the results we set out to achieve collectively – saving one million children by 2030 – and whatever we do will never be enough. Looking at the world we are confronted with a huge inequality - 80% survival rate in high income countries, and a survival rate of 20 to 30% in low-income countries!

Yet, our view of the world must be one that is full of hope, and the Annual Report reflects this. Everything we do, in the smallest or largest organisation, is filled with this certainty that the world is a fairer place today than it was yesterday, even though there is much to be done. As we approach 2030, the faces of the one million children we will save become clearer, more visible. This is our commitment to History.

I conclude on a more personal note. My term as President of Childhood Cancer International ends in October 2023. It is time to give way to a colleague and friend who, I am sure, will dedicate all his effort, wisdom, and competence to our community of patients, survivors, and their families. These three years as president were some of the most rewarding years of my life. I met dozens of people – perhaps hundreds – who dedicate their lives, as professionals or as volunteers, to alleviating the suffering of those affected by paediatric cancer. They do it under very challenging conditions. I would perhaps alter Albert Schweitzer's thought a little, saying that they are all part of the **brotherhood of those who bear the mark of hope**.

Thank you very much for all you do for children with cancer and their loved ones.



**João de Bragança**  
President, Childhood Cancer International



# 02.

## 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**  
Bindu N Nair  
India



**MEMBER**  
Kate Johnson  
Australia



**MEMBER**  
Alejandra Mendez  
Chile

## FINANCIAL AND ADMINISTRATIVE SUPPORT



Current CFO,  
Former president,  
and Honorary Member of CCI  
**Simon Lala**



Administrative Officer  
**Lex Kuiper**

# 03. Regional Committees

The CCI Board would like to acknowledge the invaluable collaboration of the CCI Regional Committee (Regcom) Chairpersons, Regcom members, honorary members, volunteers on various international and regional task teams and forums, and all individuals who committed their time to CCI and its initiatives, and put their experience and knowledge at the service of CCI.

## AFRICA

NAME	COUNTRY	ORGANIZATION
Nagm Azar (Regional Chair)	South Africa	CHOC Childhood Cancer Foundation
Daniel McKenzie (Vice-Chair)	Zimbabwe	KidzCan
Dr. John Ahenkorah,	Ghana	GHAPACC
Brian Walusimbi	Uganda	Bless a Child Foundation
Sidney Misigo Chahonyo (Survivor)	Kenya	Hope for Cancer Kids
Prof Yasser Saad-Eldin	Egypt	Alexandria Group
Dr Ihesinachi Kalagbor	Nigeria	Simara Children Cancer Foundation (SCCaF)
Naïma Otmani	Morocco	Association l'Avenir

## ASIA

NAME	COUNTRY	ORGANIZATION
Benson Pau (Regional Chair)	China, Hong Kong	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 (Regional Chair)	Austria	CCI Europe
Luisa Basset (Vice-Chair)	Spain	Fed. Española de Padres de Niños con Cáncer
Michaela Willi (Survivor)	Austria	Survivors Austria
Delphine Heenen	Belgium	KickCancer
Lejla Kamic	Bosnia & Herzegovina	Udruženje "Srce za djecu koja boluju od raka"



Harun Šabić (Survivor)	Bosnia & Herzegovina	Udruženje "Srce za djecu koja boluju od raka"
Frédéric Arnold	France	UNAPECLE
Georgia Kokkinou	Greece	Floga
Anne Goeres	Luxembourg	Fondatioun Kriibskrank Kanner
Tiago Costa (Survivor)	Portugal	Acreditar
Zuzana Tomášiková (Survivor)	Switzerland	Kinderkrebs Schweiz

## OCEANIA

NAME	COUNTRY	ORGANIZATION
Mary McGowan (Regional Chair)	Australia	Children's Cancer Centre Parent Advisory Committee
Simon Lala	New Zealand	Child Cancer Foundation
Kate Johnson	Australia	Children's Cancer Centre Parent Advisory Committee

## LATIN AMERICA

NAME	COUNTRY	ORGANIZATION
Marcela Zubieta (Regional 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
Carlos Aguilar Frias (Survivor)	Mexico	Faros de Vida
Francisco Javier Galván Villarreal	Mexico	CANICA, Centro de Apoyo a Niños con Cáncer A.C.

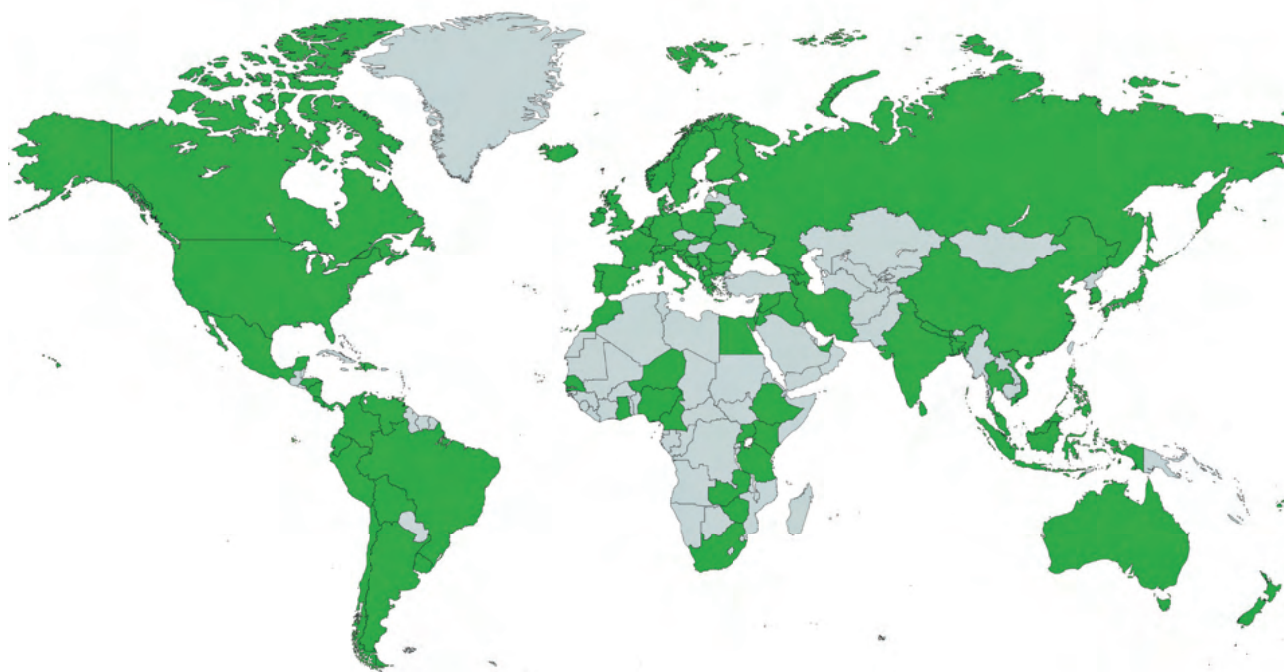
## OUR HONORARY MEMBERS

Carmen Auste was nominated and accepted as an CCI Honorary Member at the 2022 CCI Annual General Assembly (AGA). She served CCI Board between 2010 – 2019 and was elected CCI President during 2014-2016. She has been instrumental and a role model in lobbying government towards policy action for childhood cancer. Carmen joins the special group of Honorary members:

<b>NAME</b>	<b>COUNTRY</b>
<b>Anita Kienesberger</b>	<b>Austria</b>
<b>Benson Pau</b>	<b>China, Hong Kong</b>
<b>Carmen Auste</b>	<b>Philippines</b>
<b>Christine McIver</b>	<b>Canada</b>
<b>Gill Thaxter (for Geoff Thaxter)</b>	<b>United Kingdom</b>
<b>Gerlind Bode</b>	<b>Germany</b>
<b>Julian Cutland</b>	<b>South Africa</b>
<b>Jesus Maria Gonzalez Marin</b>	<b>Spain</b>
<b>Marianne Naafs-Wilstra</b>	<b>Netherlands</b>
<b>Mark Chesler</b>	<b>United States of America</b>
<b>Simon Lala</b>	<b>New Zealand</b>
<b>Sadie Cutland</b>	<b>South Africa</b>
<b>Tim Eden</b>	<b>United Kingdom</b>

# 04.

## CCI Members 2022



**CCI MEMBERS: 183 ORGANISATIONS  
IN 93 COUNTRIES**

 Childhood Cancer International <b>AFRICA</b>	<b>23 members in 14 countries</b>
 Childhood Cancer International <b>ASIA</b>	<b>47 members in 23 countries</b>
 Childhood Cancer International <b>EUROPE</b>	<b>63 members in 34 countries</b>
 Childhood Cancer International <b>LATAM</b>	<b>41 members in 17 countries</b>
 Childhood Cancer International <b>N. AMERICA</b>	<b>5 members in 2 countries</b>
 Childhood Cancer International <b>OCEANIA</b>	<b>4 members in 4 countries</b>



# 05.

## 2022 CCI Global Annual Conference Barcelona

**After two years of virtual conferences due to the pandemic, it was time to get together again, this time in Barcelona.** The satisfaction of the reunion was visible everywhere: in the halls, the corridors and meeting rooms. The countless meetings via zoom were now giving way to a physical ones. It was common to see people hugging, as well as trying to identify colleagues whom they had only “met” on a screen with mask on. Highlights of these conferences has always been the networking, the building or strengthening of friendships and connection that will facilitate future initiatives.

In addition to networking, the annual conferences are privileged moments for sharing experiences, projects, and ideas. After all, our motto is “we care, we share”. The conference was filled with topics, including a COVID-19 vaccine for pediatric oncology patients, and the response to the needs of adolescents and young adults with cancer. One of the strongest topics was the importance of support, awareness and life quality of childhood cancer survivors. In addition, we witnessed powerful stories of grieving parents and learned about support programmes for bereaved families.

There were interactive sessions during which participants discussed matters of importance for CCI, such as communication and fundraising.

As always, in accordance to our bylaws, CCI held its Annual General Assembly (AGA). The agenda was a mix of items required by our Statutes and of past and future projects – which we shared with some celebration and much enthusiasm. It was attended by 112 member organisations, and these members voted in favour of a new term of board members Rodney Wong (Malaysia) and Daniel McKenzie (Zimbabwe). Nicole Scobie (Switzerland) resigned a couple of months after the AGA. CCI is grateful to Nicole for her dedication and contribution to the cause of childhood cancer and to our community.

**Looking at the future, the Board set some strategies and projects as priorities:**

- Strategic partnerships
- Communication
- Funding development
- Global mapping
- Survivors
- Research and knowledge



Fig. 1 A group of delegates at the Annual CCI Conference in Barcelona



Fig. 2 We welcomed some new members to CCI and to the conference, such as Coalition Against Childhood Cancer (CAC2) - a collaborative network of nonprofits, corporations, and individuals from 39 states in the USA and nine countries.

# 06.

## Regional Conferences and Knowledge Sharing

### CCI ASIA

After postponement due to the Covid pandemic, the 14th CCI Asia Conference hosted in Guangzhou, China was held virtually, from July 30 to July 31. The theme was “Treatment and Care - Advances to Every Child with Cancer in Asia”. Once again the conference was done in collaboration with SIOF Asia, with great success.

**The excellent two half-day online programme included the sharing of experiences and best practices learning, introducing innovations, and adapting to changing times.** We had 30 presentations in 10 sessions; a session for the WHO Global Initiative for Childhood Cancer (GICC); a joint session with SIOF nurses; a special session on ‘Facing Challenges of Childhood Cancer Treatment and Care During the Pandemic’; and a host of other informative and interesting sessions.

We appreciate the support of SIOF LOC (local organising committee) in providing simultaneous Chinese and English translation during the online conference. This arrangement eliminated the language barrier, and went a long way to promoting CCI and SIOF. This CCI Asia conference attracted the largest number of attendees: 200 registered participants, 6,000 in audience on the Chinese channel and 5,000 in audience on the English channel!





## CCI LATAM

The CCI Latam Regional Conference took place in Punta Cana, Dominican Republic, in November of 2022. The conference attracted 38 participants from 10 countries.

The conference presented a robust programme which was jointly developed by CCI, the Pan American Health Organisation (PAHO), and St. Jude Children Research Hospital. The Education Programme included the launching of the early diagnosis campaign for the Caribbean subregion. Seven new organisations were welcomed to CCI.



During the conference a Regional Work Plan (WP) process commenced. The goals of the WP are to:

1. Increase the number of members and promote the establishment of memberships.
2. To develop and complete a strategic regional WP. A working group headed by Pilar Carbonell (Colombia) and Carlos Sánchez (Honduras) was created, that will lead in the creation of the strategic plan, that will be CCI's route plan for the region in the next 3 years.
3. Fundraising for CCI LATAM to fund additional activities in the region, and fund meetings, so as to allow for the participation of more organisations.
4. Promote communication in the region (including updating the CCI LATAM website content and the promotion of important events for the region).
5. Participation of CCI in the Mexican Alliance Meeting. Marcela Zubieta, the Regional Chairperson of CCI Latam represented CCI at the Third Meeting of the Alliance of Support Organisations for children with cancer in Mexico. At this meeting Marcela presented the results of the ENLACE project (read further on about the Enlace project in Latam under 'Strengthening the Movement' Chapter 8).



Fig. 3 Participants of the alliance meeting in Mexico

## CCI EUROPE

Every year CCI Europe organises the annual CCI Europe Conference, where we share experiences through numerous interactive sessions with our members, as well as network with our amazing childhood cancer community. The CCI Europe Conference 2022 was held in Vienna, Austria completely face-to-face from 3 to 5 June.

The CCI Europe conference 2022 was attended by 81 participants from 40 different organisations covering 25 countries. We hosted 15 sessions with 39 presentations in total, given by 35 speakers, accompanied by 2 networking dinners and a social event.



Fig. 4 CCI Europe Conference Announcement

### • Knowledge sharing

In October, CCI Europe hosted a high-level multi-stakeholder workshop on the topic of “The scientific and moral dilemma of randomizing hope in poor prognosis children’s cancers”. It was attended by international patient and parent advocates, members of the academic research community, representatives from regulatory authorities and Health Technology Assessment (HTA) in Europe and the United States. The workshop aimed to present the topic of randomizing trials, with focus on the challenging conundrum of reconciling the need for scientific rigour with the need for children and families to retain hope. A major take home lesson from the workshop is the importance for all stakeholders to continue to work collaboratively. It is only through engaging in discussions and forums to build common understandings that efforts to reconcile or mitigate the tensions between different stakeholder groups can progress.

**We proudly present: CCI Europe Gold Webinars.** A major achievement by CCI Europe’s Capacity Development team was the development of an educational webinar series. Based on a 2021 survey among CCI Europe members about their educational needs, a schedule of educational webinars for CCI Europe’s member organisations and other stakeholders (such as SIOPE) was created.

In order to increase knowledge exchange and information transfer among European CCI members, a digital “Knowledge Hub” was developed and launched in December 2022. It is populated with new resources continuously.



Fig. 5 Gold Webinars

#### • **ALADDIN: learning about new drug development**

In June 2022 the EU-funded educational project about new drug development “ALADDIN” kicked off, with CCI Europe being one of the two patient organisations involved, alongside CCI Europe member Solving Kids’ Cancer (UK). The aim of ALADDIN is to build an innovative, multi-stakeholder and structured framework with an educational programme tailored to the needs of the different actors, that is sustainable in the long-term and takes advantage of the expertise and work already initiated by the ACCELERATE platform.



# 07.

## Global Campaigns and Awareness

**ICCD: INTERNATIONAL CHILDHOOD CANCER DAY**  
15TH FEBRUARY 2022

- **The Tree of life Campaign**

ICCD, held each year on 15 February, is an important day for children with cancer across the world. In partnership with SIOP, in 2022 we launched an Advocacy Toolkit to help advance care for children with cancer globally. This was accompanied by the creation of a 'Tree of Life' in virtual and physical formats in many countries in the world.



- **2022 ICCD campaign: #through your hands**

The 2022 campaign paid tribute to the numerous health care teams across the globe, the contributions and positive impact they have made on the lives of children and adolescents with cancer. In support of this, members of CCI and SIOP were invited and had the opportunity to get involved in three levels of action:

- **Action One: International Level. Tree of Life website**

CCI and SIOP members were encouraged to invite stakeholders including patients, families, and health care team to participate in the virtual, interactive Tree of Life platform. They decorated their hands and posted their “message of appreciation” to health care teams or “messages of hope”.

All in all, 826 handprints from 72 countries were received in 2022.

- **Action Two: National Level. Special events or initiatives**

All the childhood cancer-focused NGOs, hospitals, and institutions were encouraged to create ICCD 2022 special events or activities. This could include a physical Tree of Life in their setting or in continuation of their previous ICCD events promoting this year's theme of 'Better Survival is achievable #throughyourhands'. ICCD event reports across countries are shown on the ICCD activity map of the ICCD website.



• **Action Three: Regional Level. Advocate for Action**

Members were encouraged to engage with active organisations and treatment centres in their region (according to the six WHO regions) so as to collaborate in hosting high-level ICCD 2022 events (virtual, live or hybrid) involving key stakeholders (i.e. political leaders, legislators or parliamentarians, key staff from the Ministry of Health, other relevant ministries, WHO Regional Offices, influencers and prime movers).

**Numerous activities campaigns around ICCD were organised by almost all of our members all around the world.** We received many reports on the campaigns and activities that were organised. Capturing all of these stories and reports in this document is impossible and thus below is just a sample of some other stories and reports received.

## AFRICA

**TAPCCO**, Tesfa Addis Parents Childhood Cancer Organisation, Ethiopia carried an awareness raising events for ICCD by hosting an art exhibition with professional artist and children's art in Addis Ababa, with dignitaries present at this event.



**Fig. 6** Awareness raising event hosted by TAPCCO

**CHOC**, Childhood Cancer Foundation South Africa, celebrated ICCD with a national campaign called Flip Flop day, which raises essential funds for social workers (for paediatric oncology units), accommodation facilities, transport assistance, nutritional support, and for its awareness and advocacy campaigns.



**Fig. 7** Flip Flop Day

## ASIA

**Aroh-Giving Hope**, India organised a 'ICCD – 22 RUN FOR A CAUSE'.

This virtual marathon aimed to create awareness and of and why we need to celebrate Childhood Cancer Day - to honour children with cancer, and to provide them with support. The event occurred all over India and the funds raised through will be used for the treatment of children and adolescents with cancer. Aroh-Giving Hope also organised, in the children's hospital, a Magic Show, games and a Tree of Life with their colourful handprints.

**Hope Child Cancer Care India**, social workers and volunteers distributed childhood cancer awareness leaflets at a public areas in Kerala, India. The day was commemorated by performing flash mobs, playing music, and distributing childhood cancer awareness brochures. In addition, doctors, hospital staff, volunteers, and the general public made colourful handprints on the tree of life canvas, and distributed awareness leaflets to the general public.

**The Indian Cancer Society** had a virtual session by the team of psychologists for Childhood cancer survivors; and survivors recorded their videos and created tutorials and shared their messages with support groups as well as care givers.

**Yayasan ANYO Indonesia** organised an event entitled 'YAI's efforts to save Indonesian children from cancer'. YAI held a webinar on cancer in children for primary health-care centre medical personnel in Eastern Indonesia. The goal was that cancer in children can be detected early, quickly referred for further examination and, if positive for cancer, the child is immediately treated – to improve recovery and survival rates.

**Yayasan Kasih Anak Kanker Indonesia (YKAKI)** held a series of events on the theme 'Better Survival is Achievable #throughyourhands' with a series of haircut events, flash mobs, a cultural parade, a bazaar, Zumba dances, a blood donation event and the selling merchandise. In addition YKAKI collaborated with Bera-ni Gundul to host offline and online Public Awareness campaigns on the 'Signs and Symptoms of Childhood Cancer'.

**Yayasan Onkologi Anak Indonesia (YOAI)** in collaboration with Nurse Associations, organised education for health workers in the form of virtual meeting, which was attended by around 1,700 nurses and 500 paediatricians from all over Indonesia. Additionally, YOAI created a virtual Art Show for children with cancer.

**CHANCE Association, Lebanon**, collaborated with the SWIM association to organise an environmental awareness event on the importance of the environment and its impact on health. Many cases of cancer are the result of pollution and can be minimized if the WHO Sustainable Development Goals are respected and the environment is well preserved.

A giant beautiful mural made by the children along with two international artists was left in the fishing port of the coastal town of Amchit, conveying a strong message of awareness and hope, and a nice reminder to keep our environment and sea clear of pollution to minimize the risks of cancer.

## EUROPE

In Europe ICCD was once again marked by an online Policy Event that was organised by SIOE Europe and hosted by leading childhood cancer supporter Member of the European Parliament (MEP) Loucas Furlas. The event was dedicated to the impact of the General Data Protection Regulation (GDPR) on childhood cancer research.

CCI Europe's committee members Delphine Heenen and Zuzana Tomášiková were speakers at the event, highlighting the importance of laying out the research plan in plain language, adapting the information to patients, and they emphasized the important role of parents and survivors' organisations in research projects, ensuring that the patient's interests are consequently taken into account.



Fig. 8 (above) Celebrations by Federación Española de Padres de Niños con Cáncer Spain.



Fig. 9 (left) Zuzana Tomášiková, CCI speaker at the Policy Event

**Spain's Federación Española de Padres de Niños con Cáncer**, and its 22 member associations, actively participated in ICCD. Events were organised at the national level with the presence of the Minister of Health, and at the regional and local level with the presence of regional presidents and mayors. In addition, the Federation has for the last 10 years run a schools' campaign, which featured thousands of Trees of Life.

**The P. A. V. E. L** association of Romania organised an exhibition of paintings in two major hospitals with oncopediatrics wards and on Facebook.

**Firefly, Croatia**, arranged a panel discussion entitled - "The fight doesn't stop by leaving the hospital!" with a focus on survivors and the importance of supporting children in fighting malignant diseases. Zagreb's Electric Tram and Firefly marked the day by placing flags with the Firefly logo and a golden ribbon on the city's trams; an awareness raising event near main square in Zagreb; and a webinar for the "KosaRi" Medical Students' Association on mental health with an emphasis on the psychological health of children and families during active treatment.



## LATAM

Throughout Latin America, CCI members carried out various activities to commemorate the ICCD. Fundación amigos del Niño con Leucemia y Cáncer (FANLYC) in Panama, held a campaign - digitally and on the main city streets - called ChocaLas5 (a term widely used in Panama) in order to raise awareness among the population and share updated information of childhood cancer in Panama and the world. In turn, the community was invited to contribute to programmes to help children with cancer.



Fig. 10 Choca las 5 Campaign

**In Colombia**, the Fundación Colombiana de Leucemia y Linfoma, had a campaign highlighting the work of the health personnel of the pediatric Oncology service by publishing a video based on the ICCD campaign theme of #throughtheirhands. In addition, they participated in a Ministry of Health forum on Comprehensive care for childhood cancer, ending in a media briefing.



Fig. 11 Ministry of Health Forum in Colombia

**In Brazil**, on ICCD 49 members of the large association of CONIACC had a campaign on the recognition of the early warning signs and early diagnosis of childhood cancer. This campaign involved numerous local events, and it was broadcast by some local television channels.

**In Chile**, Fundación Nuestro Hijos commemorated this day with the visit of the then-future Minister of Health, Dr. Begoña Yarza, at the Rehabilitation Center of the Foundation. The event was also used to launch the “The Legacy of Tomiii11” campaign, about a youtuber boy who reached 10.6 million subscribers, and who died of brain cancer in 2021

### • Celebrating Gold September

Traditionally childhood cancer awareness month known as Gold September is marked by the lighting up in gold of many famous landmarks around the world, including these captured by the US collaborative network of nonprofits - CAC2. Gold ribbons are also typically used to commemorate this day, by being worn, or by hanging large ones on buildings, and in a myriad of other ways. Lighting monuments and buildings in #gold or decorating them with gold ribbons are powerful means to draw attention to childhood cancer.



Fig. 12 Illuminated buildings throughout the world



## CCI Europe raised awareness on two levels:

- Sharing facts on childhood cancer, and the immense challenges cancer brings to the patients, survivors and families
- Connecting the facts to the work CCI Europe is

The region started communicating the Gold September campaign already in August 2022, when they, through interactive posts, engaged an audience to play quizzes and to see if they know the true meaning of Gold September and the Gold Ribbon.



Fig. 13 Engaging Posts for Social Media

The European childhood cancer community thanked the European Parliament for putting children with cancer in the spotlight, by illuminating the EU Parliament. Several Members of the European Parliament (MEPs) were present at that event, where we had the opportunity to meet many of them and thank them for their efforts towards improving childhood cancer challenges.



Fig. 14 The Basilica of Guadalupe in gold for Gold September celebrations in Mexico

Mexico carried out various awareness events and digital media campaigns for Gold September. The old Basilica of Guadalupe building was the venue for the closing of the golden month, and on September 30 it was “painted” gold. In addition the famous La Minerva building was illuminated in gold, along with other buildings, in Guadalajara, Jalisco, Mexico, Los Arcos, the Jalisco State Congress, the Degollado Theatre, Arcos Providencia, the Children’s Heroes Monument, Paseo Chapultepec and the Stampede!

In Brazil, CONIACC marked Gold September by a campaign on the signs and symptoms of childhood cancer. The advertising material circulated in the country through banners, billboards, bus doors, advertisements in newspapers and magazines, posters, flyers, jingles and videos for electronic media, as well as urban furniture (bus stops) and t-shirts. In this very creative campaign children’s characters appear in imaginary situations within people’s daily lives, such as in the picture of the gorilla playing the guitar.

Fundación Nuestros Hijos from Chile, illuminated the front of the Government Palace called “Palacio de La Moneda”.



Fig. 15 Gold September in Brazil

For September TAPCCO of Ethiopia had a number of activities, media coverage, as well as social media activities and posts. Gold September appeared in a total of 15 mass media features or articles. In addition , TAPCCO organised an art and craft exhibition in a prominent Addis Hotel, plus a walk in Entoto Park with a partner organisation called Plogging Ethiopia.



Fig. 16 Gold September in Chile



Fig. 17 Gold September in Ethiopia

### • The PPIE Campaign

CCI Europe ran the European Patient and Public Involvement and Engagement (PPIE) campaign with the message is “Nothing about us without us”. This is to emphasises and ensure the involvement and engagement of pediatric oncology patients in research. This project had a number of steps:

1. A survey on the awareness of PPIE among healthcare professionals, patients and their relatives.
2. A fictitious research process run with a group of patients and HCPs in a workshop to demonstrate that patient involvement can work in research from the outset and is even conducive to its quality and precision.

3. The research results of this workshop was translated to an educational video about PPIE and presented in a broad social media campaign, with the purpose of sharing the results of the study with the public - and not just in a scientific paper.

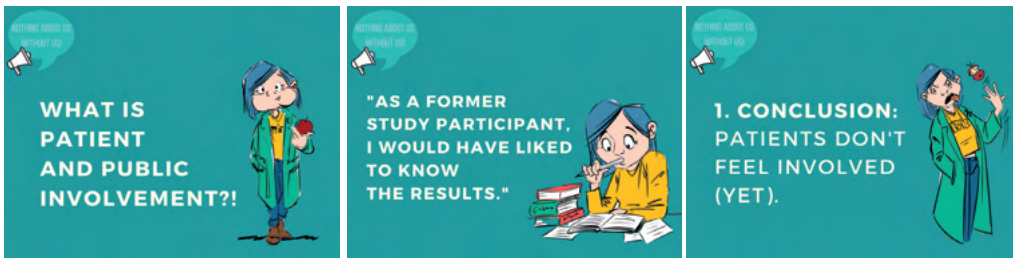


Fig. 18

# 08.

## Strengthening the Movement Capacity Development

**In 1994, when CCI (initially called ICCPO) started we were 11 organisations from 11 countries.** Today we are more than 180 organisations, in 93 countries, with a presence on all continents. Most of our members have moved from essentially providing emotional support, to more expansive activities and services, and have programmes ranging from advocacy and influencing policies; raising awareness; improving the rights of parents and of children/young adults affected by cancer; as well as survivors; to providing essential and practical support (such as medication, transport and accommodation). It has always been the purpose and the goal of CCI to bring together organisations to share knowledge and help support and develop each other. Today, as the collective voice of this community, CCI is an essential player on the international stage: we are in forums at the highest level, we participate in numerous international working groups, and we develop global campaigns so that the voice of childhood cancer is increasingly stronger.

This growing reality of our expanded role was increasingly becoming incompatible with a fully voluntary CCI Board (each member with their own personal and professional lives) – and no global staff. CCI was facing a serious problem of responding to demands, challenges and opportunities. Thus, thanks in part to the financial support of one of our member organisations, the Board decided to hire an Executive Director (ED) who would take a greater responsibility in ongoing operations, and guarantee professional and continuous management. After an extensive selection process that involved interviewing several candidates, we chose Carl Queirós, who had already been Chair of CCI-Africa, a member of the international Board and also the CEO of CHOC, our member in South Africa. Welcome, Carl, for a stronger 2023.

Some of the regions have also increased their capacity by hiring or acquiring additional staff. CCI Europe has a very strong staff team of seven staff members which cover number of portfolios and projects, including communications, project coordination, survivor follow up and advocacy.

With funding support by the PKW Charitable Foundation of Hong Kong, CCI Asia engaged Christijana as a regional Secretariat, who started in September 2022.

### ENLACE

Supported and led by Fundación Nuestros Hijos (FNH) of Chile, The Latam region launched an impressive programme called Enlace that assists other members organisations in the region to assess both their organisations and their programmes, and then assist them to address weaknesses and build their capacities.



Enlace consists of 2 stages aimed at institutional strengthening of these organisations:

1. **Self-assessment and self-analysis of organisational capacity.** 7 basic criteria are evaluated that measure the minimum aspects that an organisation must have to carry out its work: legal, administrative and programmatic consolidation, as well as other useful elements to generate sustainability and growth. At first each organisation makes a self-assessment of its compliance with the 7 minimum organisational development criteria. Secondly, peer organisations reviews the assessment and documentation and give their evaluation, and makes suggestions for improvement. 14 organisations from 10 Latin American countries have participated.
2. **Technical training.** This stage aims to improve the technical capacity of organisations and its programmes in a specific topic of interest, either with the intention of assisting them implement a programme that is not included in their care, or improving an existing programme. This stage includes structured courses, on-site technical internships and knowledge and resource sharing.

This fantastic project is already demonstrating some good results with participating organisations, and CCI is so impressed by this initiative that we hope to roll it out to other regions.



Fig. 19  
Enlace Programme in Latam initiated by  
Fundación Nuestros Hijos of Chile

# 09.

## Survivors

The progress of technology, the betterment of public health policies, the quality of diagnoses, and the intervention of civil society organisations that support the families of children and young people diagnosed with cancer, means that (fortunately) we have more and more survivors. However, as we always say, a survivor's journey doesn't end when they finish their treatments. It is necessary to continue to monitor the physical health of these survivors, and that (importantly) we do not neglect their mental health.

**The International Childhood Cancer Survivors Week**, held in the last week of June, is an annual campaign initiated by CCI. It is a week to put spotlight on Childhood Cancer Survivorship, raise awareness on challenges survivors go through, and to advocate for improving the quality of life after cancer.

**In partnership with SIOP**, CCI once again organised a webinar dedicated to survivors, with the title Childhood Cancer Survivorship Late Effects and Mental Health: Challenges and Solutions. The first part consisted of presentations by health professionals from Mexico, Denmark, USA and India. In the second part we had a round table made up of survivors, parents and siblings of children / young people diagnosed with cancer, coming from Chile, Indonesia, Kenya, Portugal, Nigeria and Lebanon. Despite all the geographic and cultural differences evidently some problems are universal and affect all survivors. Like last year, this webinar was attended by hundreds of people from dozens of countries and, for the first time, it had simultaneous translation into Chinese, so that we could reach this important community. The numbers are a clear indication of the interest of this type of meetings.

**The CCI Europe campaign for Survivorship challenges 2022** focused on showing the work of CCI regarding survivorship issues in Europe, and engaging the audience. Content was shared throughout social media channels. In this campaign we introduced the Survivorship Pillar and showed what the pillar working group members are active in. Tiago Costa, CCI Europe Committee Member and Survivor Representative, talked about his experience on advocating for survivorship issues on the European level, and the importance of being involved as patient.

Advocate Zuzana Tomasikova, CCI Europe Committee Member and Survivorship Pillar Lead, talked about long term follow-up care infrastructure and socioeconomic discrimination of childhood cancer survivors.

### **EU-CAYAS-NET: The European Network of Youth Cancer Survivors**

CCI Europe, together with Youth Cancer Europe and a consortium consisting of other European patient organisations and institutions in the field of CAYA cancer, was selected for an EU-funded grant to establish the "European Network of Youth Cancer Survivors", which kicked off in September 2023 and will end in August 2024. This "EU-CAYAS-NET" project aims at developing a "European Youth Cancer Survivors Network" alongside an interactive virtual platform. The network will foster social networking, peer support, knowledge-exchange, and aims at improving:

- **The quality of life of survivors** (including mental health, education & career support, follow-up care and transition)
- **The care for adolescents and young adults (AYA)** with cancer
- **Equality, Diversity and Inclusion (EDI)** along the whole treatment and survivorship trajectory.

**EU-CAYAS-NET is the first EU project that is coordinated by CCI Europe.**

For more information on what we are doing and to join our activities, come and visit our project platform [www.beatcancer.eu](http://www.beatcancer.eu)!



European Network of  
**YOUTH CANCER SURVIVORS**

**Fig. 20**  
EU-CAYAS-NET

### **CCI Asia Survivor Network – Late Effect Survey**

Back in 2018, survivors participating in the survivors meeting in Asia discussed the possibility of doing a survey about survivorship and late effects. A working group was formed during the 2019 CCI conference, led by Patrick Yip and a questionnaire was developed.

#### **The objectives for the survey are:**

- Find out the level of understanding of survivors about late effects of childhood cancer
- Briefly assess the quality of survivors' life after they had cancer
- Encourage survivors to take self-care of their health conditions
- Provide a basis for advocacy for better education of late effects to survivors

The Late Effect Survey conducted by CCI Asia Survivor Network was launched on 1 Aug 2022 and closed on 28 February 2023. The suitable number of participations enabled good analysis. The results will be shared in 2023.

On June 25, the Fundación Sanar Niños con Cáncer de Colombia held the Sixteenth version of the National Day of Pediatric Cancer Survivors. Under the slogan “A reunion for life”, survivors, patients, families, allies and friends of SANAR gathered at the Compensar Calle 94 auditorium in Bogotá. Attendees filled the Sanar tree of life with messages, learnt about the stories of the Exemplary Survivor nominees and lived a morning in which life was celebrated. The winner of the Fabio Restrepo Ángel Award for Exemplary Survivor 2022 was Leonardo Sosa Campos, a survivor of acute lymphoblastic Leukemia who today is part of a theatre group made up of pediatric cancer survivors that invites survivors to see cancer in a different way.

**The Latin American network of Survivors**, Faros de Vida, produced different postings on social networks with two main areas. The first one is members recalling the signs and symptoms with which they were diagnosed to raise awareness about the importance of timely diagnosis. The second is where survivors briefly recount their history during treatment and what they do in the present. This is to send a message of hope to patients.

**FNH of Chile** supported the launch of the national network of survivors called “Luz de Esperanza” (in Spanish) / the “Light of Hope” network. The main reflection of the group of young members is that childhood cancer experience impacts a person for life for the long term, and there are many challenges that a survivor faces as obstacles to a full life. The group calls for profound social change to address the obstacles to access to mortgage loans, the lack of mental health support programmes, the need for assisted fertilization programmes, and blockages to access to private health plans (these plans often exclude survivors for pre-existing conditions – i.e. including cancer).



**Fig. 21** Exemplary Survivor 2022 awarded to Leonardo Sosa Campos - National Day of Pediatric Cancer Survivors in Colombia



**Fig. 22** The launch of the National network of survivors, “Luz de Esperanza”, by Fundación Nuestros Hijos, Chile



**Fig. 23** Kelvin Kashaija, survivor/thriver graduates



# 10.

## Networking and Partnerships

There are various important and key areas that have led to the success and growth of CCI, and networking and partnerships are two of these.

Our community is vast: we are parents, family members, professionals (healthcare and others), volunteers or survivors. Despite our differences, it is in the service we provide to children and young people diagnosed with cancer and their families that we come together, as equals. With Covid-19 movement and travel restrictions, and in a globalised world and where a substantial part of communication is virtual, the face-to-face dimension of human interaction was often lost. Yet it is crucial for the effectiveness of human relationships. At least occasionally, the impersonality of the screen must give way to the human contact, to face-to-face interactions. That said, all networking (in-person or remote) is a decisive tool for sharing knowledge and experiences, and to provide a better service to our own local childhood cancer community.

CCI has entered into collaborations with numerous entities, for various purposes, but ultimately all for the same purpose: for better survival and better survival rates. While, in an ideal world, we would have wished to have more partnerships and collaborations, we are aware that our human, financial and technical resources are limited - we don't know how to do everything, and we can't do everything. We will thus here highlight, acknowledge and commend our main global partners, without whom we would not be able to do what we do.

- **WHO**

For leading the Global Initiative for Childhood Cancer (GICC), and for recognising the key role of the CCI in this.

- **SIOP**

For their partnership in various annual campaigns, helping to keep the cause of childhood cancer in the spotlight, and strengthening the voice of our community.

- **Fondation La Roche-Posay**

For believing in CCI, for their financial support, and for supporting us in the development of projects that will decisively strengthen our member organisations, and enable CCI to have a great positive impact for the cause of childhood cancer.



- **St Jude's Children's Research Hospital**

For general and technical support in a number of areas, as well as and for all their initiatives that contribute decisively to achieving the objectives of the GICC. St Jude is at the forefront of advancing cancer treatment and moving towards a cure. In addition, several CCI member organisations are part of the ALSAC (American, Lebanese, Syrian Associated Charities) programme to build members capacity, particularly in fundraising and awareness, and systems and structures.

- **CCI Latam in a partnership with 'Together' by St. Jude,**

Worked to offer this education platform to the entire CCI Latam network. The site contains trusted resources and educational tools.

- **CCI Latam partnered with PAHO**

On different projects, especially in the creation of psychosocial standards of care.

These are the partners at the global and regional level, but at national and multinational levels there were many partnerships - too numerous to mention here - but all greatly appreciated, as without these we would not achieve what we are able to achieve jointly.

# 11.

## Special Projects and Member Projects

### UKRAINE

Almost as soon as the war started, CCI set up the Ukrainian Childhood Cancer Emergency Fund to raise funds for children and adolescents, and their families, affected by the war. Funds raised assisted those affected with traveling (costs fleeing the Ukraine, regrouping families and other); medical supplies and cancer treatment; housing; and daily expenses (food and basic necessities).

Our efforts to support our Ukrainian childhood cancer community were communicated widely. CCI and CCI Europe used numerous social media channels to disseminate the information and reach out to as many people as possible. The first post about the Fund reached more than 62,000 people and had almost 300 re-shares.

Still on the Ukraine, the SAFER Ukraine project is a partnership involving CCI Europe, St Jude, other partners in Ukraine, the Polish Society of Pediatric Oncology and Haematology (PSPOH), and an international network of hospitals and governments in creating a Supporting Action for Emergency Response in Ukraine (SAFER Ukraine). It is a humanitarian effort launched following the invasion of Ukraine with the mission to aid Ukrainian children with cancer and blood disorders to receive high quality medical care, in Ukraine or abroad, through capacity building and international collaboration. At the time of writing the SAFER Ukraine collaborative facilitated the support for over 1,300 patients and their families in 21 countries. The scope of support varies based on the patient and family needs and includes translation of medical records, connecting with clinicians in the countries where families fled war, as well as medical evacuation and patient referral to the long-term care facilities abroad.

CCI-E's mission in this programme is:

:

A list with short descriptions of our ongoing projects can be found on our website.

 <b>INFORM</b> <p>We make sure all CCI-E's members are updated on a monthly basis. We bring awareness of the SAFER Ukraine role to the public through conferences and publications.</p>	 <b>SUPPORT</b> <p>We continuously support patients and their families who fled Ukraine by providing psychosocial tools and connecting them with local services.</p>	 <b>REUNITE FAMILIES</b> <p>We facilitate family reunifications in collaboration with the SaferUkraine team, Tabletochki and the respective local member coordinator.</p>
 <b>IDENTIFY</b> <p>We identify in each European country a contact point able to commit to welcome and support Ukrainian families including transportation, lodging, daily needs, and psycho-social needs.</p>	 <b>LIASE</b> <p>We liaise between Ukrainian organisations and CCI Europe's representatives in each country by providing support and resources in case challenges occur.</p>	 <b>MANAGE</b> <p>We manage the Ukrainian Emergency Fund in order to be able to finance immediate needs and requests.</p>

<https://ccieurope.eu/projects/>



Fig. 24 Ukranian Childhood Cancer Emergency Fund

## SUPPORT PROJECTS

- **Inequality of availability of medication, and of access to treatment and care**

While patients and parents in some countries can take it for granted that commonly used medicines in the treatment for childhood cancer are available in their countries, this is not the case in many developing / resource challenged nations. In Ethiopia, for instance, our member TAPPCO conducted a campaign to raise funds to acquire medicines - both those directly for the treatment of cancer and other related medications. This was done with government support, and the Ethiopian Pharmaceutical Supply Agency (EPSA). Similarly funds were raised through the Ethiopian Diaspora – Ethiopians living in Toronto raised thousands for medication and support of the children and parents in Ethiopia.



Fig. 25 September 2022, Donation of medicine and supplies from EPSA, Addis Ababa, Ethiopia

**In Tanzania**, for the estimated 4,500 children who develop childhood cancer every year, the ability to afford travel, medical care, and associated costs is a distant dream. The partnership between Muhimbili National Hospital, CCI member Tumaini La Maisha, and the National Children Cancer Network (NCCN), has resulted in comprehensive support that includes everything from chemotherapy, accurate diagnostics, and medical training to play therapy, transport, nutrition, accommodation, and much more at 13 sites across the



country. One of their key future goals is to partner with more hospitals across Tanzania with the goal of ensuring that no child is more than 4 hours away from a treatment centre.



**In Kenya, Hope for Cancer Kids (HCK)** has several projects but their signature one is their National Hospital Insurance Fund (NHIF) Support Programme. HCK enables children and adolescents from low-income backgrounds that are unable to access quality cancer treatment due to the prohibitive costs, by raising funds and paying for their health insurance cover – the NHIF. This covers in-patient and out-patient hospital fees in public hospitals for the child and their family. This saves lives. In 2022 HCK supported an average of 180 children a month!

**Rainbow Children's Village - KidzCan, Zimbabwe.** KidzCan opened its first ever Home Away From Home - a restorative halfway house for children undergoing treatment and their caregivers, who often come from remote areas. The home will reduce treatment abandonment and improve the quality of life for patients and family members.

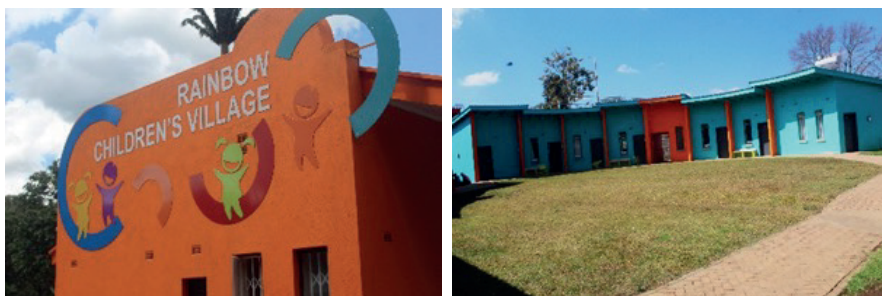


Fig. 26 KidzCan's Rainbow Childrens Village

**CCI Europe used a report and campaign to bring attention to inequalities in childhood cancer.** This report sets out for the first time the evidence on childhood cancer inequalities in the European region and examined the patterns that emerge at national and regional levels of childhood cancer incidence, patient and caregiver experiences, and short - and long-term outcome for patients.



Fig. 27 CCI Europe's inequalities campaign

**Childhood Cancer Family Support Society (CCF Support)**, Canada raises approximately \$125,000 - \$150,000 per year to support families of children with cancer that are struggling financially. This support is determined and provided through Social Workers at the British Columbia Children's Hospital. Despite this monumental effort, with an average of 130 children diagnosed with cancer each year in, unfortunately the need is greater than what CCF can provide.

These are just examples of support programmes offered by our members which have a massive positive impact for children and their families. We commend and all CCI member organisations around the world like who provide essential care and support - without which many children and adolescents with cancer simply wouldn't get the treatment and care they did so desperately need.

# 12.

## Communications and Social Media

In year 2022 we professionalised our communications by working with a communications agency who supported our efforts.

For the year, our main goal was to create a larger and engaged online CCI community.

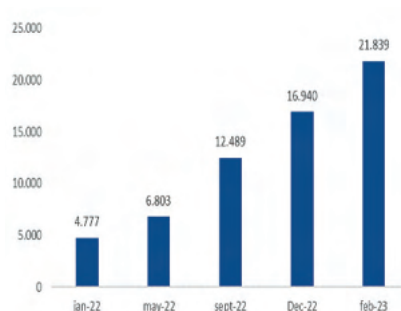
### Secondary goals:

- Share helpful information to improve the quality of life of childhood cancer patients, families, and survivors
- Create / promote awareness
- Encourage and facilitate advocacy
- Inform / educate our community
- Create a supportive enabling environment for childhood cancer initiatives
- Show our impact (mainly, but not only, through sharing successful stories from member organisations)

### • Growth In CCI Digital Community

The community increased by 255% in 2022.

500,000 people viewed our content, and there was a high degree of interaction with the content.

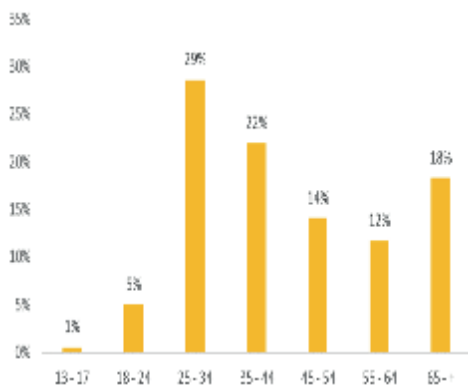


### • CCI Communications Channels 2022

- CCI website
- Facebook
- Instagram
- LinkedIn
- Twitter
- E mailing (monthly newsletters)

## • CCI Digital Community

### By age



## • Communication Strategy

- The aim was to have very human and personal content, by sharing real stories, which are visually attractive and seeking audience interaction.
- Each month we selected a “Topic of the Month”
- Resources, relevant conversations and information was shared.



# 13.

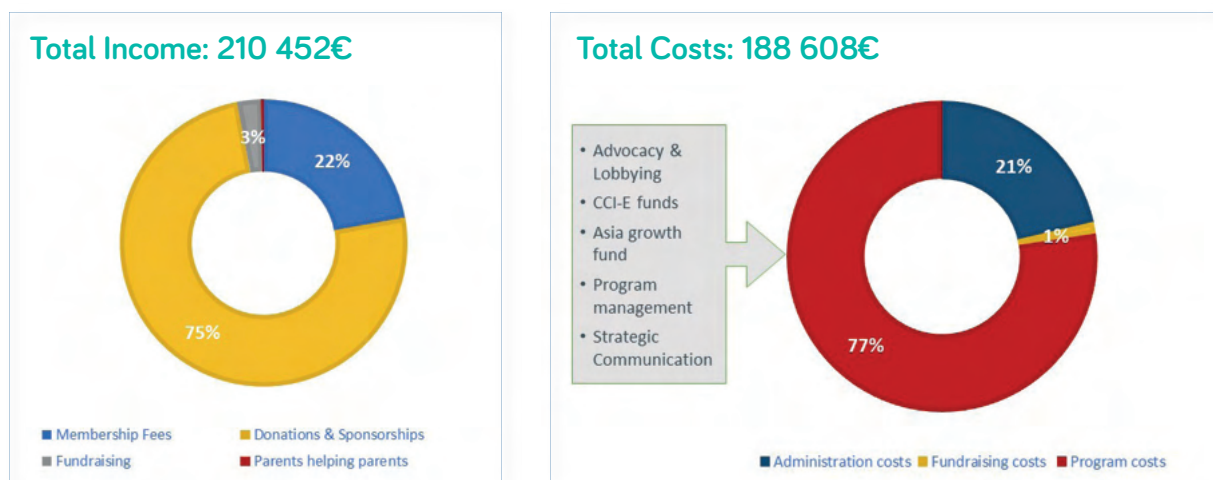
## Financial Review

### CCI GLOBAL (HEAD OFFICE)

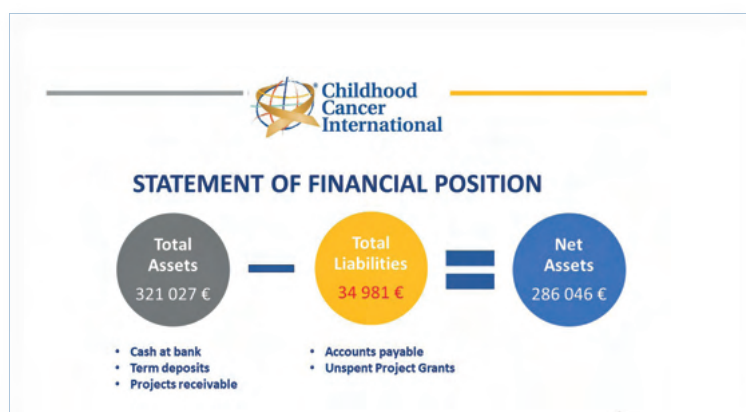
Overall CCI ended 2022 with a surplus of €21,844 (all amounts are in Euros), a total income for the year of €210,452, and total expenditure of €210,452. The result is favourable when compared with budgeted deficit of € 8,600.

Compared with the previous year, 2022 was very similar (across all income and expenditure).

A highlight for the year was the resumption of the La Roche-Posay funding which contributed €125,105 to global programme and operations. Administration costs make up 21% of total expenditure, but remained below 20% of total revenue, which is in line with acceptable standards for the non-profit sector. The graphs below provide further information on the association's income and expenses



As the graph below illustrates, the financial position of the organisation remains healthy with net assets totalling €286,046 as at 31 December 2022, with a small liability amount compared to assets.

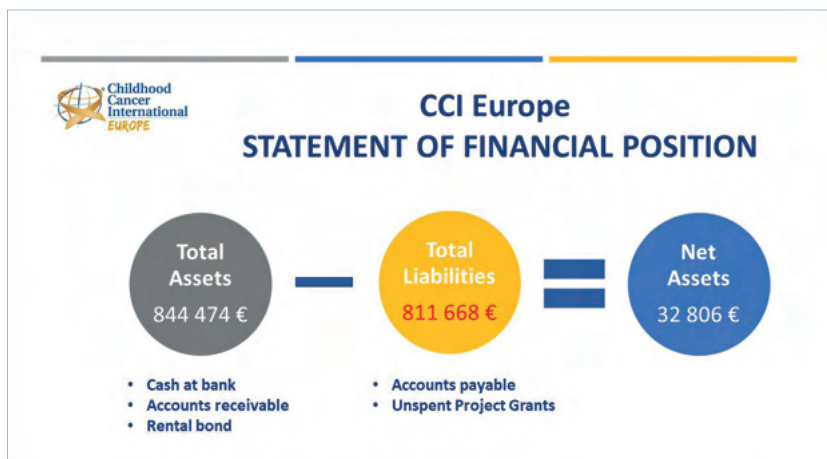


## CCI EUROPE

CCI Europe is a branch of CCI, its finances form part of CCI's, and CCI has overall responsibility for CCI Europe's finances and activities. While CCI is registered in the Netherlands, CCI Europe is a registered entity based in Austria and under Austrian statutory regulations.

Total income for the year for Europe was €363,056 (Euros) which included restricted project grants, donations and sponsorships of €304,925. Europe's income for 2021 was only €71,054 as it was impacted by the covid pandemic, so there has been a very healthy recovery and growth in 2022.

Total expenditure for the 2022 financial year was €360,547, which included operational expenses of €191,592. The surplus of income over expenses for the year was 2,509 Euros. The graph below shows the financial position of CCI Europe as at 31 December 2022, with €32,806 in net assets. As is evident from the graph and the figures, much of CCI Europe's income is restricted income allocated to projects, hence the high figure in terms of total liabilities. The branch is in a positive state with sufficient assets to cover all liabilities and costs, and a net asset surplus.



A copy of the full set of audited Financial Statements can be obtained from the CCI Head Office Secretariat.



## LEARN MORE ABOUT US

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

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