



ANNUAL REPORT 2020



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1. Message from the President

"All sorrows can be borne if you put them into a story or tell a story about them."

Attributed to Karen Blixen

Writing an opening text for an Annual Report is always an incomplete gesture. It is true that a Report is a sum of frames, in this case of our 2020 film. But it is insufficient, because it does not translate everything: it alludes to what we have done, it does not refer to what we are; it mentions events but does not describe feelings. A photograph, however sharp it may be, does not reveal the impact of the human touch. We are what we do, and the way we do it.

2020 was the year of the pandemic; the Annual Report has a chapter entirely dedicated to this theme, to the impact of COVID-19 in almost all our member organizations and the families they care for: loss of funding, postponement of medical appointments, fears about visits to the hospitals, unemployment, an increased need of the support we already provide to so many people. The pandemic also prevented us from holding our annual conference, which is an important time for our community to do networking, to share experiences, to take the opportunity to revisit old friendships and forge new ones. Nevertheless, in a virtual way, we held our Annual General Assembly, and this Report mentions it.

2020 was also the year of the explosion in Beirut, which left a trail of more than 200 dead, 7.000 injured and 300.00 homeless, affecting hospitals where children with cancer were being treated. Even in a financially difficult year, the CCI community managed to come together to help the Lebanese organizations which have done an extraordinary work under such difficult conditions. 2020 was a especially devastating year of natural disasters all over the world, affecting local populations. The Philippines and Nepal were

particularly affected by typhoons, volcanos, and floods, respectively, that destroyed homes, making the quality of life of families of children with cancer more difficult, forcing them to reorganize their daily lives. Once again, the community came together to help in whatever way possible.

However, as you can see in the Report, 2020 was also a year of achievements, of intense activity. Because of the events mentioned above, our community had to reinvent itself. Part of our lives may have been suspended by the pandemic, but cancer diagnoses did not, and our children need us. We know that “resilience” is a word that all parents get used to from the moment their child is diagnosed with cancer, and that each of our member organisations is the sum of all our individual strengths. Therefore, we used that inner capacity to continue our daily work, to ensure that no child would miss a treatment or an opportunity to be happier.



Our vision, that ***children and adolescents with cancer benefit from the best possible treatment, care, and support, anywhere in the world*** remains as actual as when we drafted it. However unfair, the idea expressed by Bono that ***where you live in the world should not determine whether you live in the world*** is a constant reminder that this crusade against childhood cancer and against the inequities is far from being over.

Fred Rogers, the famous American television host, author and producer once said: ***“when I was a boy and I would see scary things in the news, my mother would say to me: look for the helpers. You will always find people who are helping.”*** Who are the helpers? Sometimes it can be a partnership – with La Roche-Posay foundation, with FOCP, with UICC, with St. Jude or SIOP – or it can be a program. The Annual Report highlights the Global Initiative for Childhood Cancer (GICC), a powerful umbrella under which a vast community works together, recognizing that we are all equal (even being different) because we have a common goal: ***to save one additional million lives in the next decade.***



It is attributed to Virginia Woolf the notion that ***nothing has really happened until it has been described or recorded.*** Organizing an Annual Report is more than complying with a legal requirement or putting news in a chronological order. Although in a necessarily incomplete way, preparing this document is telling the story of a past year, to make real the lives of

thousands of people who are protagonists of our journey: patients, survivors, parents, health professionals, policy makers, influencers, volunteers, anonymous people who devote their time, energy, and love to the service of others. In our story there is a broken world and a better world, there are mentors and heroes; in our story the monster can be the indifference or the lack of investment, and the moral can be the confidence that everything can be overcome if we are not alone.

This opening text is an invitation: ***Pay us a visit, get acquainted with what we do, from Asia to LATAM, from Europe to Africa, from Oceania to North America.*** But this opening text is also an acknowledgment to the people, in the most powerful country or in the most remote place, that never cease to work for the children, adolescents and young adults diagnosed with cancer, even in the most difficult circumstances.

This opening text is an acknowledgement to **Childhood Cancer International.**

On a more personal note: 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.

João de Bragança
President, Childhood Cancer International



2. Board of Trustees



PRESIDENT
Until October 2020
Ruth Hoffman
USA



PRESIDENT
After October 2020
João de Bragança
Portugal



VICE-PRESIDENT
Rodney Wong
Malaysia



TREASURER
Mary McGowan
Australia



SECRETARY
Luisa Basset
Madrid



MEMBER
Daniel Mckenzie
Zimbabwe



MEMBER
Nicole Scobie
Switzerland



MEMBER
Marcela Acuna
Chile



MEMBER
Elected in October
Nagm Azar
South Africa

3. Global Initiative for Childhood Cancer

It is estimated that each year around the world there are more than 400,000 new cases of children with cancer, but almost half will go undiagnosed. It is also estimated that “globally there will be 13.7 million cases of childhood cancer between 2020 and 2030, and that about 3.4 million of these children will be in low-income countries, with about 6.9 million children in lower-middle-income countries. (...) Left unaddressed, we estimate that a total of 11.1 million children will die from childhood cancer between 2020 and 2050, if no additional investments are made to improve access to health-care services of childhood cancer treatment. Of this total a staggering 9.3 million children will be in low-income and lower-middle-income countries, accounting for 84.1% of all children who will die from cancer in that period.”

In 2017, during the 70th World Health Assembly (WHA) held in Geneva, Switzerland, the World Health Organization’s (WHO) 2017 Cancer Resolution was unanimously adopted by WHO Member States. This resolution, which was an update from the 2005 WHO Cancer Resolution, challenged member states to address the inequity in access to treatment, with an emphasis on outcomes for all people living with cancer, including the special population of children, adolescents, and young adults.

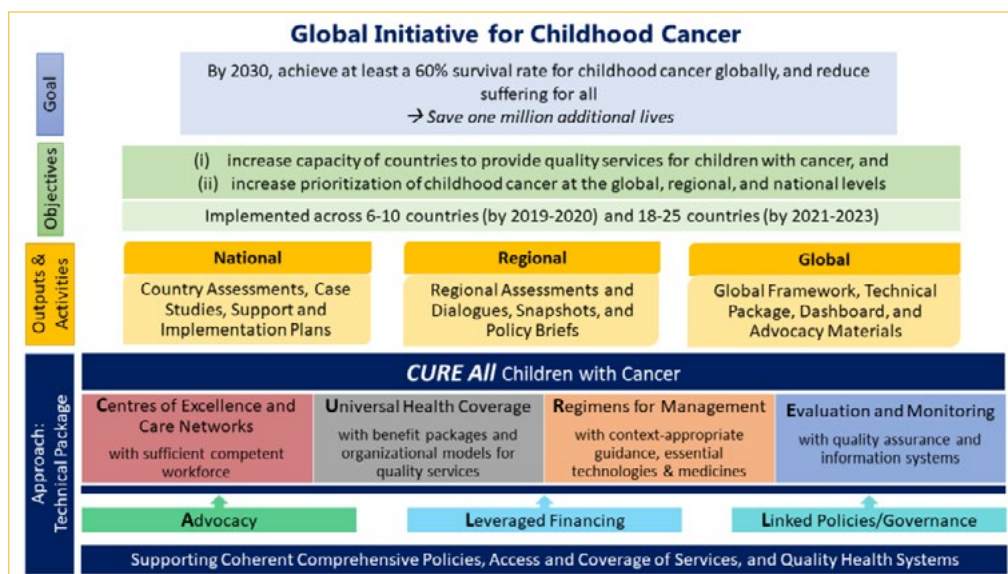
With this mandate, in 2018, the WHO launched the Global Initiative for Childhood Cancer. Its goal is to support governments in building and sustaining high-quality childhood cancer programs. The Target Goal of the WHO Global Childhood Cancer Initiative is to achieve at least 60% survival for all children with cancer by 2030 while reducing suffering. This will save an additional one million children’s lives over the next decade.



THE JOURNEY: GLOBAL INITIATIVE FOR CHILDHOOD CANCER



This initiative, with concerted efforts at the global, regional, and national levels, brings together stakeholders from around the world towards a shared goal of saving lives and reduce suffering for children with cancer.



Goal, objectives, outputs and activities and approach for the global initiative

Childhood Cancer International is proud to be a Non-state Actor in official relations with the WHO. Comprised of 176 member organizations in 93 countries around the world, we are the largest organization representing the voice of the families of children with cancer. As such, we play a major role in the translation of this target goal into the concrete actions needed to save our children's lives.

In September 2020, to collaborate closely with the 6 WHO regional offices, CCI nominated representatives as follows:

WHO - HQ INTERNATIONAL

| NAME OF CCI REPS | TYPE OF REPS | COUNTRY | CCI MEMBER ORGANISATION |
|---------------------|-------------------|----------------------|---|
| Ruth Hoffman | HQ Representative | USA | ACCO & CCI, President |
| Benson Pau | HQ Representative | 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 | Kidzcan 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) |

WHO - South East Asia (SEARO), Region

| NAME OF CCI REPS | TYPE OF REPS | COUNTRY | CCI MEMBER ORGANISATION |
|------------------------------|--|------------|--|
| Poonam Bagai | 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 - Western 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 MacGowan | 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 |

WHO-CCI Country Connection/Collaboration:

One way or another CCI has been present in many events related to the Global Initiative for Childhood Cancer. The following reports reflect only a part of what we are doing on a continuous basis.



Myanmar:

Benson Pau visited WHO Myanmar office in Yangon during the February trip to Myanmar. Together with Dr Tint Mo Hnin of Yangon Children’s Hospital (YCH), he met with Dr Stephen Paul Jost, WHO Representative to Myanmar and exchanged the work of WHO and CCI in Myanmar. With immediate follow up conference call at WHO office with Dr Dinesh Jeyakumeran, Technical officer for diet & nutrition, in Nay Pyi Taw WHO office. Dr Dinesh agreed to help review the Nutrition Champion Facilitator Guidebook, when the draft in English and Burmese are available, as CCI-YCH-WHO country level collaboration. Hopefully, the guidebook can be used for other LMIC countries of the Global Initiatives for Childhood cancer under WHO SEARO in future.

Southeast Asia Region (SEAR):

The launch of Southeast Asia Region Childhood Cancer Network (SEAR CCN) by WHO SEARO with the first meeting was held through the zoom platform on 21 August 2020. The participants included heads and childhood cancer care team members from 11 member institutions and Ministry of Health representatives from six Member States. Poonam Bagai, representing Cankids...Kidscan and CCI Asia, was invited to present on “Patient navigation and family engagement for patient centered care” in the 1st SEAR CCN meeting.

During the meeting Poonam also spoke about the important role that CSO can have in achieving the GICC goals and on the need for improvement in patient navigation and family engagement for patient centered care. She also expressed commitment to contribute to the activities of SEAR CCN with recommendation as follows:

- Involvement of CSO and Parent/Survivor Groups alongside institutional members in the practice network
- Capacity building
- Quality improvement
- Common platform for communication
- Innovative network activities
- Advocacy for childhood cancer
- Promoting existing collaborations

There were two more SEAR CCN dialogues in 2020 with Poonam Bagai representing CCI for attendance:

- October 2020: Access to Essential Medicines in Childhood Cancer
- November 2020: Challenges in Diagnosis and Care Plan Implementation in Childhood Leukemia

LATAM:

CCI was also actively involved with SLAOP (Latin American Society of Paediatric Oncology) in the WHO GICC, having Peru as the index country for the region of the Americas. The Childhood Cancer Law, national policies, and educational material can be referred as important milestones in the region.

In February 2020 The Just Because Foundation From Trinidad & Tobago participated in the PAHO meeting: Health System Strengthening for Childhood Cancer in the Caribbean, presenting Childhood Cancer Civil Society Involvement Parent / Patient Support. (PIC7 IAF)

Implementación de la Iniciativa en la región de las Américas

FASE1:

Diagnóstico situacional

FASE2:

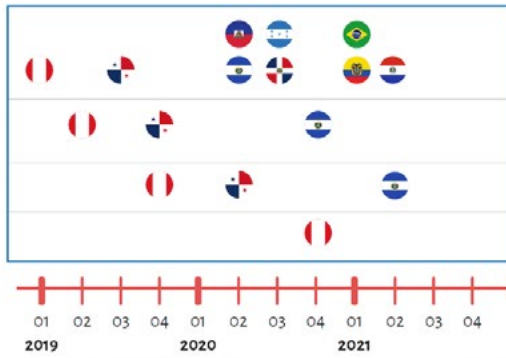
Planeamiento, costeo y financiamiento.

FASE3:

Implementación

FASE4:

Monitoreo y modificación



PAHO



Implementación de la Iniciativa en la región de las Américas



Phases of Country Action

Assess

- Perform stakeholder mapping
- Collate and acquire data for informed decision-making, preferably founded on population-based cancer registries

Plan, Cost & Finance

- Set priorities
- Formulate cancer programme or plan priorities, articulated in and integrated with relevant national strategic documents

Implement

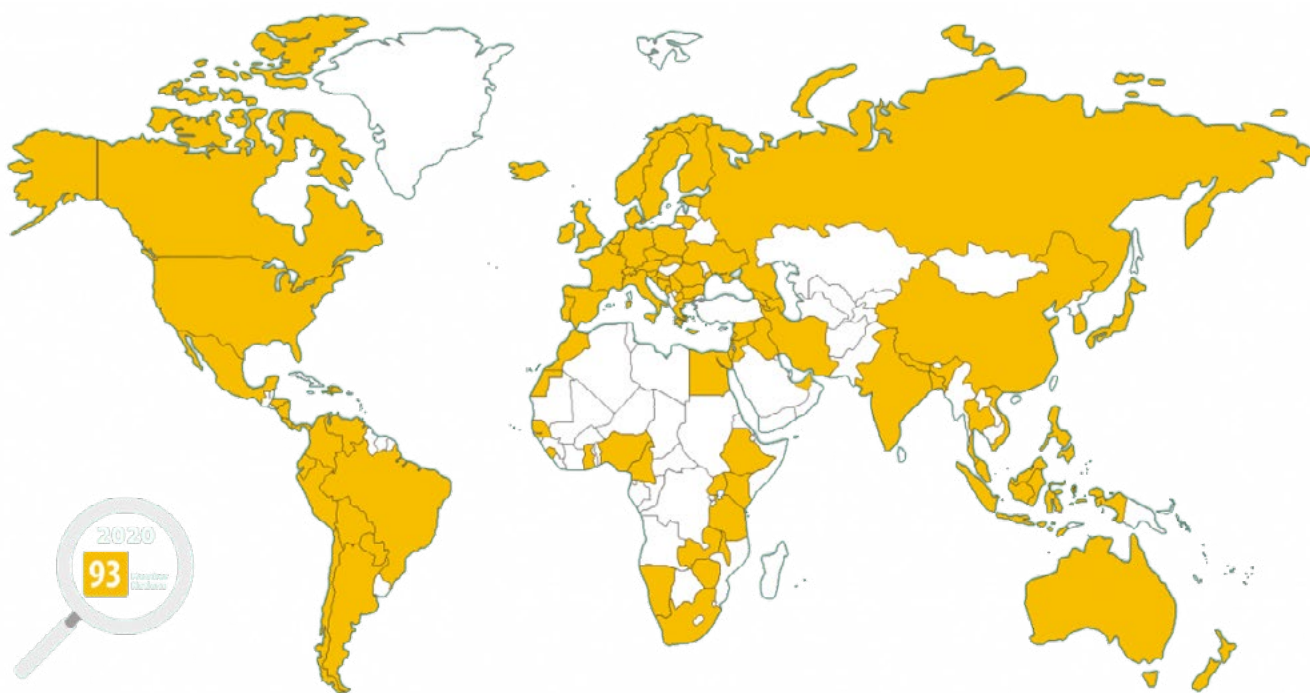
- Cost programme
- Identify sustainable funding founded on domestic sources
- Explore extra-budgetary support from stakeholders as catalysts

Monitor & Modify

- Select minimum dataset for monitoring of programmes
- Integrate information systems (national, facility and community levels)
- Strengthen cancer registries and research to guide programme modifications

Pictures: courtesy of Dr. Liliana Vasquez (SLAOP)

4. CCI MEMBERS 2020



CCI MEMBERS: 176 organisations in 93 countries

| | |
|--|----------------------------|
|  Childhood Cancer International AFRICA | 22 members in 16 countries |
|  Childhood Cancer International ASIA | 45 members in 22 countries |
|  Childhood Cancer International EUROPE | 66 members in 33 countries |
|  Childhood Cancer International LATAM | 35 members in 17 countries |
|  Childhood Cancer International N. AMERICA | 4 members in 2 countries |
|  Childhood Cancer International OCEANIA | 4 members in 4 countries |

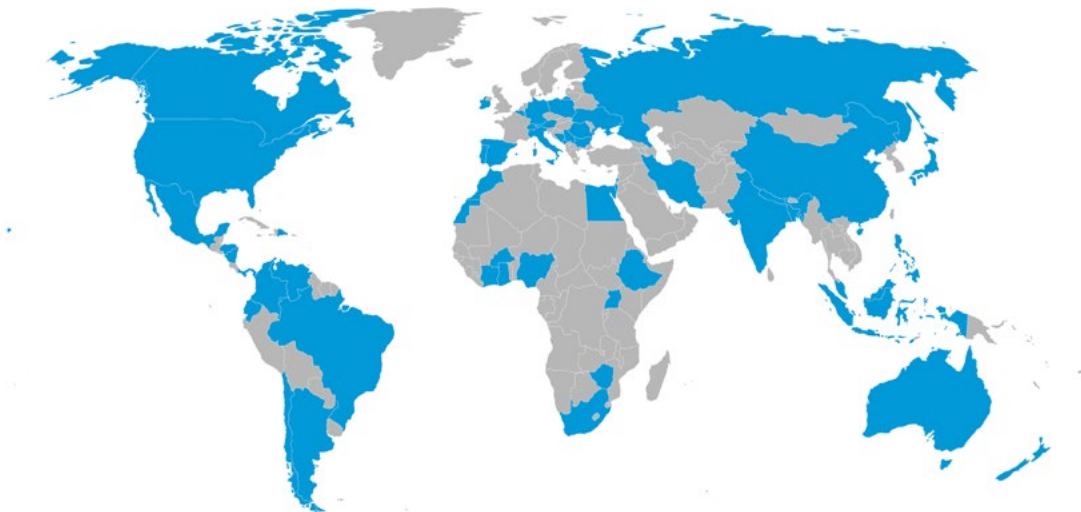
5. COVID-19

INTRODUCTION

For a substantial part of the world, “pandemic” is a neologism. They may have used it for the first time in 2020, when COVID-19 invaded our homes, our routines, our lives. In fact, people have used it so much that for some organisations the word of the year in 2020 was pandemic, whereas for others it was lockdown, or even quarantine.

From a health perspective, there is an obvious relationship between COVID-19 and people with respiratory problems, obesity, or other diseases. In a sense, the relationship between the virus and paediatric oncology is more tenuous: children and adolescents, even if immunocompromised, are less likely to catch or transmit the virus. Nevertheless, the community of children with cancer was strongly affected by the pandemic: either directly, due to possible parental disease, or less directly, due to the damages caused to the world around them, a fundamental comfort bubble for their fragile balance.

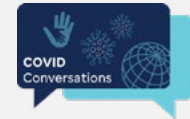
THE SURVEY



During the pandemic, CCI realised that it should assess the impact of COVID-19 on the perception of access to cancer treatment of patients, families, survivors and NGOs, and also its impact on the emotional and psychosocial aspects of paediatric cancer care. To raise awareness, either locally or globally, it was important to know what was happening.

The results of the survey were presented at a seminar on the 4th of June 2020, organized in collaboration with St. Jude Children’s Research Hospital. The pandemic was just beginning, but our community was already feeling its effects.

Childhood Cancer International COVID Impact for NGOs, Parents and Survivors



**Moderator
Nicole Scobie**
President, Zoë4life
Board Member, Childhood
Cancer International



Luisa Basset-Salom
International representative of
Fed. Española de Padres de Niños
con Cáncer (Spain), Board
Secretary Childhood Cancer
International



Miguela Caniza, MD, MPH
Director Global Infectious Diseases
Program, St. Jude Global



Jaap den Hartogh, MA
Policy officer at Dutch Childhood
Cancer Parent Organization,
PanCare Board member, CCI
Europe Committee member.
Survivor representative



Dr. Muhammad Saghir Khan
Tawam Hospital
SIOP-PODC Co-Chair
Abu Dhabi, UAE



Lars Hjorth, MD
Associate Professor, Consultant
Paediatric Oncology &
Haematology, Department of
Paediatrics, Skåne University
Hospital



Ruth Hoffman, MPH
CEO American Childhood
Cancer Organization,
President Childhood Cancer
International, Co-Founder
Access Initiative



Melissa Hudson, MD
Department of Pediatrics College of
Medicine University of Tennessee
Health Science Center and Director,
Cancer Survivorship Division St.
Jude Children’s Research Hospital



Daniel McKenzie
Executive Director,
KidzCan Children’s Cancer Relief
Foundation
Harare, Zimbabwe

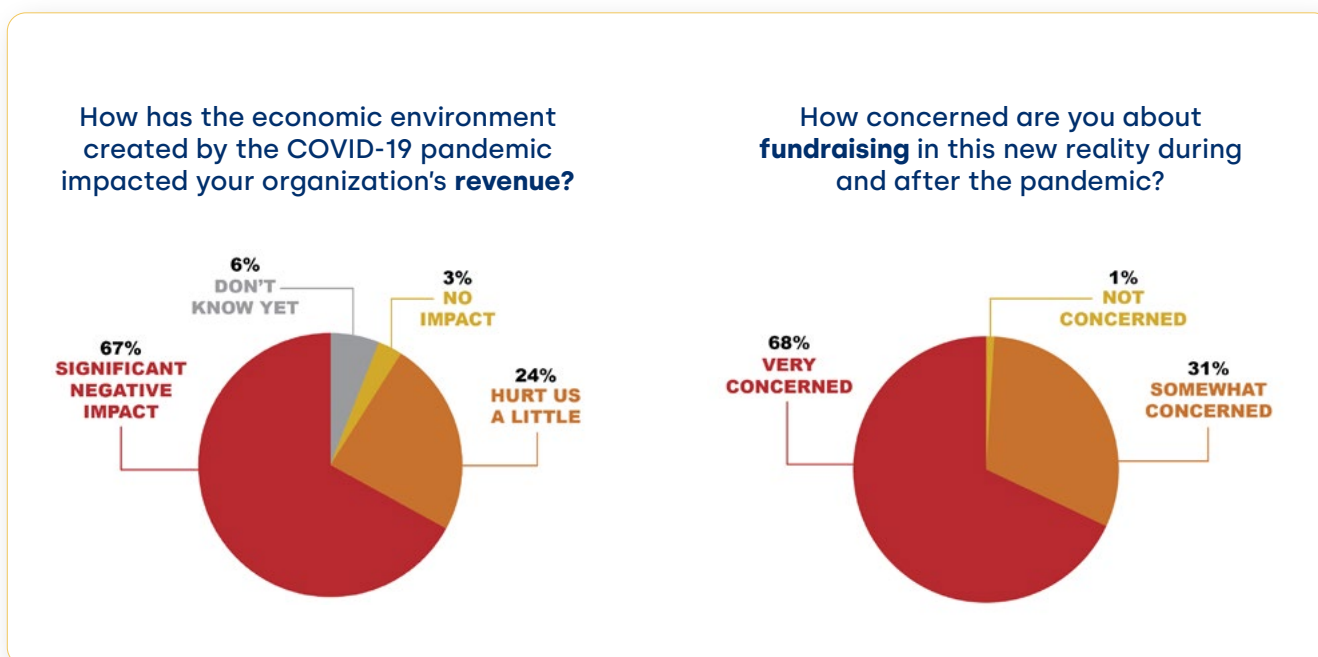
69 CCI member organizations from 52 countries, covering HICs and LMICs, completed the survey, which addressed 4 main areas:

- 1. Impact for NGOs and Parents (financial and service related)**
- 2. Treatment and Medical Questions (worries about access to medicine, delays in treatment, telemedicine)**
- 3. Survivor Issues**
- 4. Emotional Impact of the Pandemic, Psychosocial Issues, Knowledge, and Information Requirements**

It’s not within the scope of this text to share all the results, only to highlight some areas that can explain major challenges we faced and are still facing.

Some results

What was the financial impact of COVID-19 on our member organization's?



The graph is self-explanatory, but perhaps the impact of the pandemic - or what was known about the pandemic at the time - could be illustrated by two comments, chosen among many other:

- “We are providing food and transportation so that the kids can get to their appointments in time.”
- “Maybe the organisation does not exist as it is in few months.”

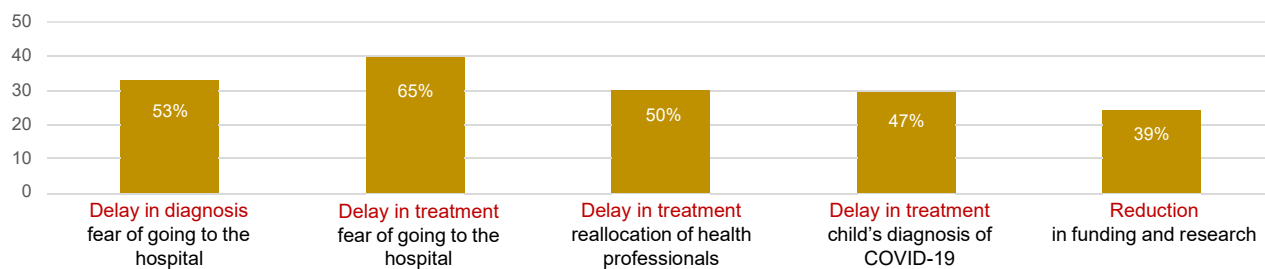
The lack of funding has a direct influence in our NGOs:

- 85% of the NGO's had to modify some, many or all their programs.
- 70% had some to all programs cancelled.
- 1/3 rd had to reduce or close family homes. For families who must travel great distances for treatment, these family homes were essential to maintaining care.

The survey also sought to find out the impact of COVID-19 on treatments.

Some comments mention that lack of public transportation due to lock-down, or that “some original drugs which [were] produced abroad are discontinued and it is difficult or impossible to buy them now”.

Are parents and patients in your region **concerned** about:



There is a general idea that telemedicine will play an important role in the future. At the beginning of the pandemic this was something new, and we wanted to know what the families' concerns were.

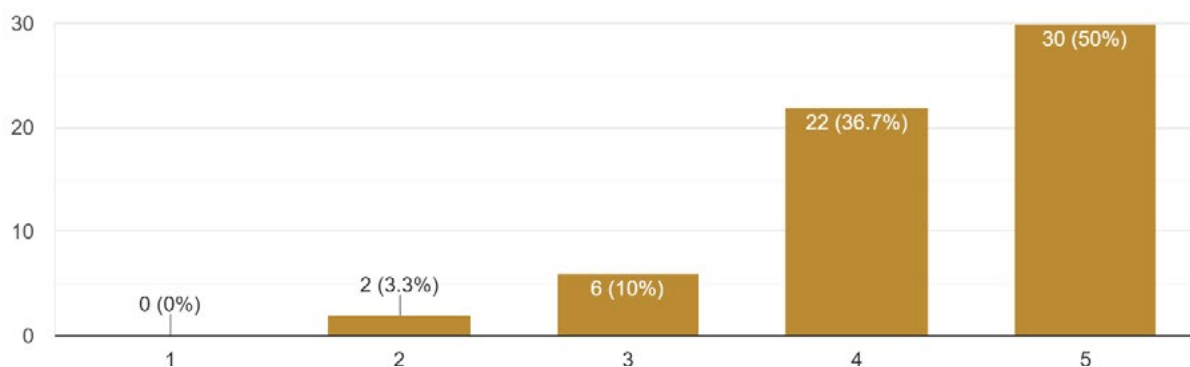
- “The fear of missing some important detail is great”
- “Will be needed more and more in the future. Needs to be leveraged”
- “Communication has to be improved, giving parents enough time to ask all the questions they would raise in a face-to-face visit.”

Last but not the least, we wanted to understand the emotional impact.

Please rate on the following scales the emotional impact of the pandemic on parents and patients in your region

Fear/worry scale

60 responses



What were the main reasons behind this situation?

- Entire health system focused on COVID-19
- Limited number of people who could accompany the patient
- Survivors worried about their vulnerability to Covid-19
- Many parents had lost income, which was hugely stressful.

Conclusions

The impact of COVID-19 on our member organizations has a direct impact on the wellbeing of our children: there are less programs to families, and services like homes/transportation, registries, nutrition programs are at risk. Many NGO's (with much less resources) had to provide food or financial support to families. 2020 was, in fact, the year of the pandemic.

You can review the entire webinar following this link:
https://players.brightcove.net/1942203451001/rJ5hfo9P_default/index.html?videoId=6162023824001

You can view the slides of CCI's presentation on our website.

6. 2020 Congress

Due to the COVID-19 situation around the world, it was decided to cancel the CCI face-to-face congress scheduled to be held in Ottawa, Canada in October.

However, as mentioned in the letter to its members, CCI would hold its “own virtual Annual General Assembly (AGA) in keeping with our bylaws.” The agenda for that important meeting reflected the fulfilment of our statutory obligations but also the joy of sharing actions of the past and projects for the future



ANNUAL GENERAL ASSEMBLY AGENDA

Friday Oct. 16th, 2020 **ON-LINE**

10:30am – 12:30pm (Ottawa time-EST)

Please check your time zone. See below the time in some cities/zones

Calgary 8:30am - 10:30am
Chile 11:30am - 1:30pm
London/Lisbon 3:30pm - 5:30pm
Central Europe/ Morocco 4:30pm - 6:30pm
Nairobi/Beirut 5:30pm - 7:30pm
Dubai 6:30pm - 8:30pm
New Delhi 8:00pm - 10:00pm
KL/Manila/SGP 10:30pm - 00:30am
Tokyo 11:30pm - 1:30am
Melbourne 00:30am - 2:30am
Auckland 3:30am - 5:30am

Registration as enter ZOOM call.

Please, register with your name, the name of the organization and country.

1. Welcome
2. Approval of 2019 AGA Minutes
3. Approval of extension for submission of the annual report for financial year 2020 and grant discharge to the board
4. Annual Report and Activity 2019-2020
5. Financial report 2019 and Auditor's report
6. Incoming Board of Trustees Election
7. President & Vice-President Election
8. Action Plan 2020-2021
9. Budget 2020-2021
10. Appointment of auditor for 2020 Accounts
11. Membership applications and changes
12. Other Business
13. Place and date of General Assembly 2021
14. Closing

The AGA was attended by more than 50 member organisations that voted the re-election of some Board members: João de Bragança (Portugal) and Luisa Basset (Spain), who completed the second term, and Nicole Scobie (Switzerland), who completed the first one. We also voted and welcomed Nagm Azar (South Africa) as new Board Member.

Incoming Board of Trustees Election: VOTE

João De Bragança (Portugal) lost his 7-year-old daughter Madalena to a diffuse pontine glioma. He is President of the *Portuguese Association of Children with Cancer*. He is a mechanical engineer with a Master's degree in Literature Theory and works as a translator.



Luisa Basset (Spain) is mother of a survivor of a mature B-cell ALL diagnosed in 1990. Since then, she is involved at local, national and international levels, representing *Fed. Española de Padres de Niños con Cáncer* and is member of the CCI-Europe Committee. She is an architect and Professor at the School of Architecture in Valencia.

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

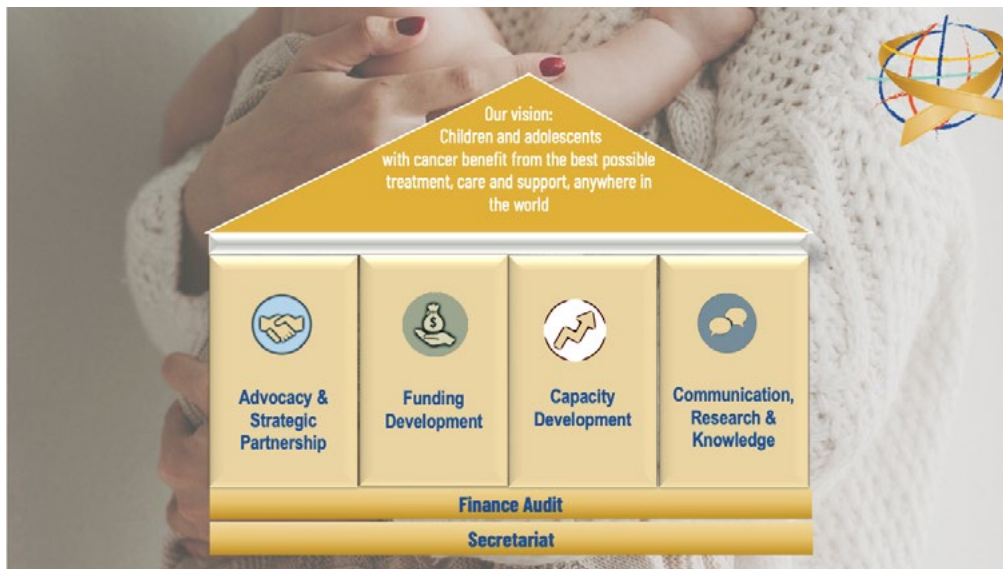


Nagm Azar (South Africa) is a parent of a survivor and has served CHOC since 1999 as a volunteer. He is married to Heloise and has two boys. He is a Financial Planner, Wealth Manager and currently serves on the CHOC board as Chairman and is very passionate about making sure that the parent and child who suffers from cancer can get the best possible support that can be provided in South Africa.

This AGA marked a turning point in the Board composition. It was the moment to vote for the election of the President and Vice-president (João de Bragança and Rodney Wong, respectively) and a time to say 'goodbye' and 'thank you' to Ruth Hoffman, who stepped down from the presidency of CCI after 3 years of dedication to our community.

As always, the AGA is a time to look at what we have done but also a time to look to the future – priorities, challenges, projects. The newly elected president shared the Action Plan for 2021 that had been prepared with the Board of Trustees and that was voted favorably by the members. This Action Plan is a roadmap that will guide the organization for the whole year, and includes, among other information, the main objectives for the year. Four areas were considered priority:

- Advocacy & Strategic Partnership
- Funding development
- Capacity Development, and
- Communication, Research and Knowledge



You can access the whole Action Plan in:

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

7. 2020 Membership Global Achievements

7.1. REGIONAL STRUCTURES

EUROPE

Chair
Anita Kienesberger

Vice-Chair
Luisa Basset

Committee Members

Anne G.

Lejla K.

Frederic A.

Nicole S.

Jaap den H.

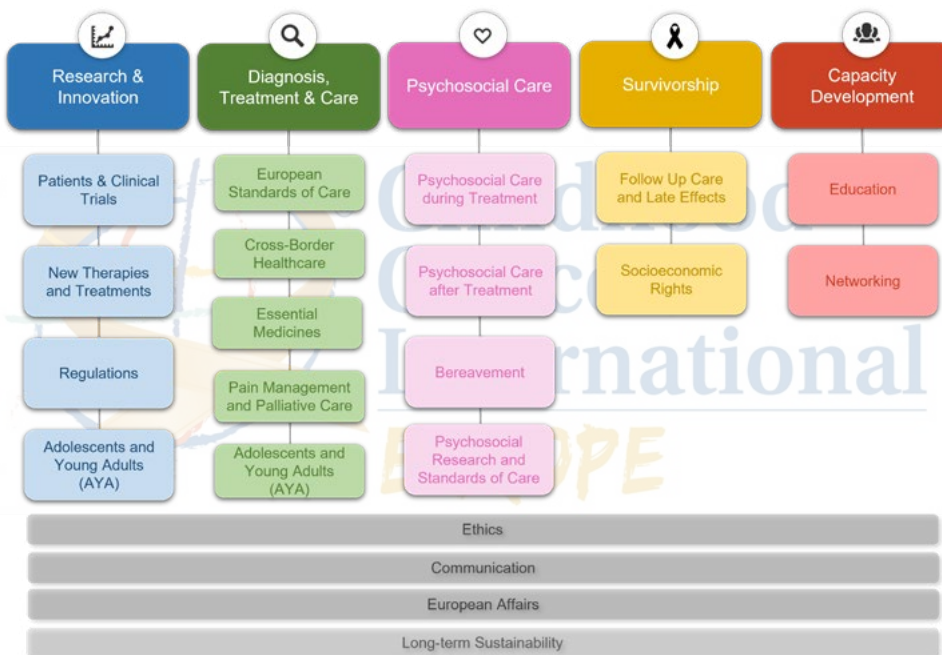
Carina S.

Zuzana T.

Harun Š.

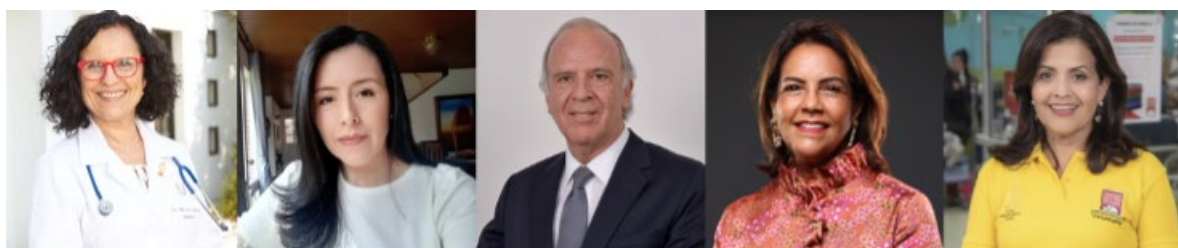
Delphine H.

CCI Europe Pillars & Subpillars



LATIN AMERICA

| CCI LATAM Committee | |
|--|--|
| Head of Committee | Marcela Zubieta : Fundacion Nuestros Hijos , Chile South America |
| Committee members | Nubia Zúñiga : Fundacion Hondureña para el Niño con Cancer H Alexandra Matus : Fundacion Amigos Contra el Cancer Infantil . Dominican Republic Miguel de la Fuente: Fundacion Peruana de Cancer Yolima Mendez: Fundacion Colombiana de Leucemia y Linfoma Observatorio PP . |
| WHO representative | Caribbean zone: Alexandra Matus Centro America: Nubia Zúñiga Sud America: Marcela Zubieta , Miguel de la Fuente |
| Special project | International, Newsletter and LATAM Web page: Oscar Barbaste , Alejandra Mendez, Marcela Zubieta International Funding development : Alejandra Mendez, Carlos Sanchez ICCD : Alejandra Mendez, Oscar Barbaste , Javier Galvan Enlace Programme: FNH Peru GICC: Marcela Zubieta SIOP PODC TF parents and survivor engagement: Marcela Zubieta / Alejandra Mendez |
| Committee Secretary | Nubia Zúñiga / Marielos Mendoza |
| Responsibilities | |
| 1-Regional Conference | Yolima Mendes , Marcela Zubieta , |
| 2-Develop parent group | Nuria Rossel , Josefina Berlinger , Alejandra Mendez, Marcela Zubieta (FNH) |
| 3-Survivor parent group Development | Yolima Mendes , Annette Becke MDr , Nuria Rosell , Aleian dra Mendez , Jazmine Fernandez , Marielos Mendoza |
| 4- Communications & Awareness Building (CCI Regional campaigns, newsletter, social media....) | Alejandra Mendez, Oscar Barbaste , Marcela Zubieta |
| 5- Membership Development &Data Management (existing/potential member contact, membership fee) | Nubia Zuñiga : Centro America Alexandra Matus : Caribbean Marcela Zubieta Sud America |
| 6-Research (useful research publications to share and publication) | Marcela Zubieta |
| 7-Strategic Partnership & Advocacy | Marcela Zubieta , Miguel de la Fuente |



From Left to right: Marcela Zubieta, Yolima Méndez, Miguel de la Fuente, Alexandra Matos and Nubia Zúñiga

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 |
| Naima Otmani | Morocco | Association l'Avenir |

ASIA



Benson Pau, Hong Kong SAR, China
- Head of Committee



Carmen Auste, Philippines
- Capacity Development:
Develop parent group in Asia
- Strategic Partnership & Advocacy



Poonam Bagai, India
- Capacity Development:
Survivor group development
- Finance & Resources Mobilization



Manal Elewah, Egypt
- Capacity Development:
Develop parent group in Asia



Roula Farah, Lebanon
- Capacity Development:
Survivor group development
- Communications & Awareness
- Research



Saideh Ghods, Iran
- Research



Gary Ho, Malaysia
- Capacity Development:
Regional Conference



Sawsan A.S. Al Madhi, UAE
- Finance & Resources Mobilization



Bindu Nair, India
- Communications & Awareness



Ira Soelistyo, Indonesia
- Membership Development & Data Management



Kohsuke Yamashita, Japan
- Membership Development & Data Management



Kazuyo Watanabe, Japan
- Strategic Partnership & Advocacy

| Name | Country | Organization |
|----------------------|-------------|--|
| Simon Lala | New Zealand | Child Cancer Foundation |
| Mary McGowan | Australia | Children's Cancer Centre Parent Advisory Committee |
| Anne Kaye | Australia | Children's Cancer Centre Parent Advisory Committee |
| Kate Crowley Johnson | Australia | Children's Cancer Centre Parent Advisory Committee |

7.2. ICCD

International Childhood Cancer Day is a global collaborative campaign to raise awareness about childhood cancer, and to express support for children and adolescents with cancer, the survivors, and their families.

The day promotes increased appreciation and deeper understanding of issues and challenges relevant to childhood cancer and impacting on children/adolescents with cancer, the survivors, their families, and the society. It also spotlights the need for more equitable and better access to treatment and care for all children with cancer, everywhere.

This annual event, created in 2002 by Childhood Cancer International (CCI), is based on our core belief that every child and adolescent with cancer deserves the best possible medical and psychosocial care, regardless of country of origin, race, financial status, or social class. It is also anchored on the premise that many childhood cancer deaths are avoidable, with timely and accurate diagnosis, availability, and access to quality essential medicines as well as proper treatment and care.



Regarding the 2020 campaign, Ruth Hoffman, in her last year as president, wrote in the CCI Newsletter (June 2020):

“The year started off with so much hope as we raised awareness around the world through our #nomoreborders campaign. The campaign was the third in a three-year series under the theme of #nomore. Year one, we raised our voices together towards a goal of #nomorecomplacency. Year two, we joined in working towards #nomorepain and #nomoreloss for our world’s youngest cancer patients, and this past February 15th, we celebrated International Childhood Cancer Day in recognition of the need to break down borders so that all children with cancer, regardless of where they live in the world have equal access to childhood cancer treatment and care.”

As always it was a time of great activity in our community.



- **ACCO’s ICCD Coverage**

On February 15, 2020, the American Childhood Cancer Organization participated in International Childhood Cancer Day by posting 9 hours of awareness on our social media outlets. Each post focused on the campaign #NoMoreBorders for children with cancer and their families, using materials developed by ACCO and distributed to CCI member organizations at

the 2019 Annual General Assembly. The message highlighted the need to stand united to make childhood cancer a national and global child health priority in support of the WHO Global Childhood Cancer Target Goals.

Throughout the day, ACCO shared statistics on childhood cancer in LMICs (<https://www.acco.org/international/>) and informed the community about how childhood cancer in LMICs affects children differently than in high-income countries. We also highlighted ACCO's financial support of Tesfa Addis Parents Childhood Cancer Organization (TAPPCO), as well as the Bless a Child Foundation in Uganda.



You can find more information on ICCD 2020 in <https://www.fnh.cl/ci/NewsCCIapril.html> and more general information on other ICCD's on: https://www.facebook.com/internationalchildhoodcancerday/photos/?ref=page_internal

7.3. ADVOCACY AND AWARENESS

AFRICA

TAPCCO Report of 2020 - Ethiopia

- **Supporters Role**

A fast food chain called Cold Stone had invited the children and parents for the opening of their first shop. In the opening event of the restaurant Minister of Culture and Tourism Dr. Hirut Kassaw was present. The children and parents enjoyed the event and children had face paint, pizza, and ice-cream.

In December 2020 we also had a virtual workout session that was conducted by five local trainers at no cost to us. It was conducted during the week of christmas.

- **Blood donation**

Jimma program also have activities to the parents and children during month of September. Luckily the number of COVID -19 cases in Jimma is much lower than Addis as a result it was able to carry out activities like blood donation, and sales of tickets.

- **Rotary Club Support**

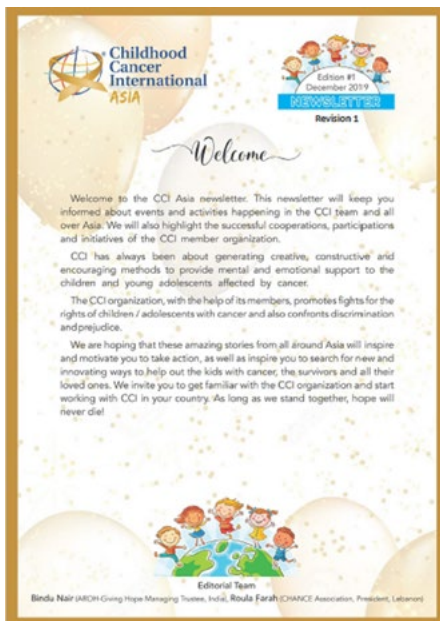
Rotary Club of Sheger District, Addis Ababa has given food support to TAPCCO in response of COVID-19 Pandemic. In collaboration with rotary club we were able to have organized an open Air Cinema for the children and parents at Seba Dereja Home. The movie selected was Madagascar and everyone enjoyed the film.

Association l'Avenir Activities – Morocco

- ICCD celebration
- Entertainment for kids
- Painting workshop
- Music class

1st Edition of CCI Asia Newsletter

The first edition of CCI Asia Region Newsletter was distributed in January 2020 and since then it has been published biannually. The idea of the Newsletter was discussed at the Regional Asian Committee meeting at the CCI conference in Lyon, France and a subcommittee for “Communication and Awareness Building” was formed and tasked with the duty of designing and publishing the Newsletter. The aim of the Newsletter is to collect, document, and thus inform the CCI members of the excellent work done by the member organizations. This helps us to be motivated and educated by learning about each other’s innovative ideas. The Newsletter is also a platform to share the news about CCI in general. In the first edition, equal representation was given to all the regions and unique stories were selected for publication and this method is followed in the later Newsletters also.



LATIN AMERICA

CCI Latam 2020 Congress, Peru

The twelfth CCI Latam Meeting was a success in terms of participation, organization, learning and proposed goals for the short and mid-term for the region.

In this meeting participates 20 delegations from 8 countries in the region plus two European exhibitors, adding a total of 63 participants, of which 11 were survivors of Childhood Cancer from five Latin American countries.

Main milestones

- The creation of the first organization for childhood cancer survivors in Latin America with the support of CCI.
- Launch of the Fondation La Roche Possay (FLRP) portal in Spanish
- Presentation of the ENLACE Institutional Strengthening project.

ENLACE Project, for the professionalization and strengthening of childhood cancer organizations in Latin America.

Proposed by Fundación Nuestros Hijos from Chile, ENLACE is a project endorsed by CCI Latam to build and strengthen organizational and professional capacity for childhood cancer organizations in Latin America. Its two main components include the auto evaluation and peer evaluation of organizational capacity, and the sharing and implementation of successful intervention models in specific technical areas. The first phase of the project started in August 2020 and is expected to finish by September 2021. Due to the pandemic, it's been adapted to an online format, with monthly meetings for lectures and discussions of organizational criteria to meet. Representatives of 14 non-profit organizations working for childhood cancer in Peru, Bolivia, Colombia, Costa Rica, Honduras, Ecuador, Paraguay, Chile, Brazil, and Mexico are participating. The participants' engagement in sharing knowledge and experiences has been key to a successful experience which is expected to grow and continue over 2021.

Communications

In January 2020 we activated the CCI Latam Facebook fan page. A new platform to disseminate CCI's work globally and regionally. <https://www.facebook.com/CCILatam>

This channel has also allowed us to share news, knowledge, and experience of our members, as well as strategic partners such as Faros de Vida, SIOP, SLAOP, PAHO, and UICC.

Oncopolicy Affairs

CCI Europe made important progress in building awareness and support of the childhood cancer policy agenda, together with SIOP Europe and PanCare, continuously involving the three EU institutions throughout 2020: the European Commission, the European Parliament, and the Council of the EU (2020 EU Presidency was held by Croatia and Germany).

Bilateral Meetings with High-Level EU Decision Makers

Throughout 2020, CCI Europe, SIOP Europe, and PanCare met bilaterally with multiple MEPs, Council of the EU representatives, and both Commissioners for Health Stella Kyriakides (2019-2024) - as well as with the Commissioner for Research 2019-2024 Mariya Gabriel.

In addition, with newly formed official European Parliament Special Committee on Beating Cancer, called BECA, the European childhood cancer community meaningfully engaged with respective MEPs in attending regular BECA Hearings and ensuring the voice of childhood cancer patients, parents, survivors and professionals is well noted.

The establishment of this committee shows the importance of the fight against cancer for the EU's future. The coming period will be dedicated to establishing a set of concrete recommendations for the Member States and the EU institutions to strengthen resilience against cancer. Hence, this is an ideal opportunity for the European childhood cancer community to ensure that children and adolescents with cancer are not forgotten.

Special Policy Event for MEPs: 'Beating Childhood Cancer in Europe'

The milestone event on 28 January 2020 was co-organised by SIOP Europe in partnership with CCI Europe and PanCare and was hosted by leading MEPs from across political groups. At least 13 MEPs from 11 countries were in attendance to discuss the priorities for paediatric cancer in the 2019-2024 EU policy term. The event succeeded to inform and mobilise MEPs on issues pertaining to equal access, sustainable research platforms, and empowering parents, patients, and survivors.

Gold Ribbon Campaign

The Gold Ribbon is the universal symbol to create awareness about childhood cancer. Since September 2019, SIOP Europe, CCI Europe and PanCare have been actively involving policy makers in the Gold Ribbon Campaign. As a result, 31 MEPs from 17 countries showed their support to the paediatric cancer cause by wearing the Gold Ribbon pin and sharing their engagement on social media.

SIOPE, CCI-E, PanCare & MEPs Against Cancer (MAC) Group Event

The MAC is a group of MEPs with a shared interest in cancer policy. Supported by its Secretariat – Association of the European Cancer Leagues (ECL), the MAC has been a close partner of SIOPE Europe, CCI Europe and PanCare in promoting a more enabling policy environment for youngest cancer patients and professionals serving them.

- SIOPE, CCI-E, PanCare and MAC event: ‘How can EU4Health and Horizon Europe programmes improve access to diagnosis, treatment and care for paediatric cancer patients?’, 08 Sept 2020

Europe’s Beating Cancer Plan

On 4 February 2020 – World Cancer Day, the President of the European Commission Ursula Von Der Leyen announced the launch of a Europe’s Beating Cancer Plan Communication meant to underpin future policy efforts in this field. The launch event was widely attended by cancer stakeholders including a delegation from CCI Europe and SIOPE Europe representing paediatric cancers. The launch of the Plan was a landmark development placing cancer at the very top of the EU policy agenda.

The European Commission conducted two public consultations to get citizens’ perspectives on the content of Europe’s Beating Cancer Plan. CCI Europe in collaboration with SIOPE Europe and PanCare made an extensive effort to encourage input from members across Europe including 3 webinars. As a result, 200 responses were sent to the European Commission calling for an appropriate focus on paediatric cancer.

- CCI Europe will continue advocating for appropriate inclusion and high visibility of paediatric cancer in Europe’s Beating Cancer Plan and its implementation.

EU Pharmaceutical Strategy: Timely Patient Access to Affordable Medicines

Launched by the European Commission on 2 June 2020, the Strategy aims to ensure Europe’s supply of safe and affordable medicines to meet patients’ needs and support the European pharmaceutical industry innovation efforts. The Strategy concept note refers among others to the evaluation of the Paediatric Regulation and mentions a plan on shortages. The stakeholder consultation process to feed into the Strategy is ongoing as of July 2020. CCI Europe together with SIOPE Europe made a comprehensive stakeholder mobilisation effort to ensure that paediatric cancer community views were well represented.

- Advocacy on improving access to medicines for children and adolescents with cancer - including in relation to innovative therapies, countering shortages, and advancing affordable prices of new expensive agents – is the key in the CCI Europe agenda.
- Advocating for a legislation that enables faster and more efficient development of innovative medicines for children and adolescents with cancer remains on the top of the policy agenda in the aftermath of the evaluation of the Orphan and Paediatric Regulations.

In addition, CCI Europe undertook a comprehensive campaign in collaboration with healthcare professionals via SIOP Europe on the EU Orphan and Paediatric Regulations, with messages supported by the European Parliament in an official Resolution that reflected in the European Commission evaluation report of the Regulation launched in 2020 together with the abovementioned EU Pharmaceutical Strategy which encompasses the result of the consultation.



EU Funding Programmes in Health and Research

EU-level support is instrumental to ensure that the urgent needs of paediatric cancer patients and survivors are not overlooked and instead become an integral part of all relevant funding programmes. The Cancer Mission Area in the EU Framework Programme for Research and Innovation and the EU4Health Programme are among the initiatives that hold promise for the paediatric cancer sector in the next 5 years.

CCI Europe continued raising awareness together with SIOP Europe and PanCare on the unmet needs and the importance of EU-level support to make progress in paediatric cancer research and ensure the sustainability of the ERN PaedCan.

Essential Medicines List for Children and Adolescents with Cancer

On the basis of the JARC Conclusions, SIOP Europe has mobilised the pan-European community of clinicians, researchers, and parents to take part in the development of a list of anticancer medicines that are essential for the treatment of children and adolescents with cancer. Hence, CCI Europe is involved within the Steering Committee of the SIOPE Essential Medicines Project.

Based on current standard treatment protocols in all paediatric tumour types, literature review, and expert consensus, the SIOP Europe Essential Medicines List will be presented to EU policy-makers and the WHO for the next revisions of the WHO Essential Medicines List for Children (EMLC).

Policy Publications

During 2020 CCI Europe jointly with SIOP Europe produced and widely disseminated several policy publications:

1 - SIOPE, CCI-E, PanCare Position Paper: ‘Beating Cancer in Europe: Let’s not forget our children and adolescents’, Feb 2020: https://worldspanmedia.s3.amazonaws.com/media/siope/documents/document/beatng-cancer-in-europe_737480.pdf

2 - European Parliament Health Committee (ENVI) Report: “Strengthening Europe in the fight against cancer: Going Further, Faster”, July 2020: [https://www.europarl.europa.eu/RegData/etudes/STUD/2020/642388/IPOL_STU\(2020\)642388_EN.pdf](https://www.europarl.europa.eu/RegData/etudes/STUD/2020/642388/IPOL_STU(2020)642388_EN.pdf)

3 - European Childhood Cancer Organisations’ Recommendations following the European Commission’s Evaluation of the Legislation for Medicines for Rare Diseases and Children and the launch of the Pharmaceutical Strategy for Europe, Nov 2020: <https://siope.eu/media/documents/recommendations-for-paediatric-cancer-following-launch-of-the-pharmaceutical-strategy-for-europe.pdf>

4 - Annals of Oncology, Access to Essential Anticancer Medicines for Children and Adolescents in Europe, Dec 2020: [https://www.annalsofoncology.org/article/S0923-7534\(20\)43223-5/fulltext](https://www.annalsofoncology.org/article/S0923-7534(20)43223-5/fulltext)

7.4. SURVIVORS

LATIN AMERICA

Start of Latin American childhood cancer survivors network

In March 2020, in the context of the CCI Latam annual meeting, ten survivors from Mexico, Honduras, Bolivia, Ecuador Colombia and Chile participated in the event and shared their experiences as survivors.

As a result of the commonalities and needs shared in the group, the Latinamerican childhood cancer survivors network was initiated, with these ten survivors as founders and the mentorship of members of CCI Latam (Yolima Méndez, Anette Becker, Alejandra Méndez, Jazmine Fernández, Nuria Rossell).



In the course of several online meetings, they refined the concept of the network, decided a name, and set their main short and median-term goals:

- The group name was decided: Faros de Vida (Lighthouses of Life), with their motto being Vivir para inspirar (To live to inspire), as they see themselves dedicated to guide and inspire children and teenagers undergoing active treatment, as well as childhood cancer survivors in their needs towards inclusion after treatment.
- Main goals are to create a directory of childhood cancer survivors from all countries of Latin America to promote links with Faros de Vida.
- Conduct a survey to stablish main needs and priorities and plan strategies accordingly.
- Build a webpage or integrate an existing one, as support and information tool.

In June 2020, the first virtual meeting of survivors of Latin America was held, with participants joining from several Latin American countries. The general take away from this encounter was that this network is highly needed, and brings the very much anticipated opportunity of connecting with peers around the continent.

The limitations of the COVID pandemic have slowed down the activities of the group, however, they are working on a survey to distribute online as their first action towards the goals of the network.

Faros de Vida expects that the support of CCI Latam, having them as ancillary group, will be decisive for the achievement of short and long-term goals.

7.5. RESOURCE MOBILIZATION

AFRICA

CHOC CHILDHOOD CANCER FOUNDATION SA

Period under review was extremely difficult for CHOC in that the country went into lockdown in March 2020. Because of Covid-19 our regions were unable to host the bulk of their internal and external events. This meant a significant reduction in income from this form of fundraising. However, with a little bit of creativity, the World Wide Web and access to a variety of digital media platforms, we were able to host a number of virtual events and campaigns. The support we received from our loyal donors, both corporates and individuals was amazing and we are truly grateful to everyone who continued to believe in CHOC and give generously, both monetary and in-kind. As a result of this and a generous bequest, we were able to reach our income targets.

Key Achievements:

- CHOC implemented its first ever Flip Flop Day in February 2020. We called on all South Africans to “have a heart...wear a sole” and we were not disappointed. Through our retail partner, PNA Stationers, and our loyal supporters, we were able to generate over R1.5 million income in our first year.
- For childhood cancer awareness month in September we ran our Be Bold Go Gold campaign to create awareness of childhood cancer in South Africa.
- CHOC was once again selected as the beneficiary of the Vodacom Super Ruby Kicking Cancer Campaign. Due to the lockdown, the Vodacom Super Rugby tournament was cancelled. However, Vodacom and Supersport committed to the R1 million donation. We are extremely grateful for this partnership and the opportunities it has provided for children and teenagers living with cancer.
- The 2020 Midmar Mile took place and once again the CHOC team in KwaZulu-Natal hosted the CHOC 8 mile swimmers who raised in excess of R400 000.
- In June 2020, CHOC called on its supported to throw on their pyjamas for our Jammin’ in your Jammies campaign which raised R50 000.

We continued to receive pro-boni services from Newsclip which enabled us to keep track of and monitor our media exposure. In lieu of CHOC’s 40th anniversary year regional events focused on this special occasion. These include the Sani Walk for CHOC, the KZN Benefit Ball, WC Benefit. The CHOC National Office hosted a Golf Day to celebrate 40 years.

We Care We Share - Emergency Support

CCI Asia assists families of children with cancer in the cataclysmic explosion in Beirut, Lebanon

On August 4, 2020, Beirut was rocked by a cataclysmic explosion at the port. The Lebanese people witnessed the largest disaster to hit its capital in years, leading to 200 dead, 6,000 injured and 300,000 people displaced in this tragedy. Three major hospitals in the city were directly affected by the blast and the healthcare system in the capital was put under extreme pressure. Healthcare professionals and emergency rooms all over the country were overwhelmed and overloaded by this tragedy. Children with cancer in Beirut were seriously rocked in their hospital beds with shattered glass, destruction, and serious injuries around them.

CCI quickly reached out to members to help Lebanon with emergency support. We raised more than EUR17,000 from 7 Asia members and 1 Italian member. The relief funds were split between the three members in Lebanon: CCCL, CHANCE, and Kids First. The funds helped the on-going treatment of childhood cancer patients in such adverse conditions.



CCI Asia assists disaster-stricken families of children with cancer in the Philippines

The Philippines was hit by two severe typhoons within a matter of days in Oct 2020. Typhoon Goni was considered one of the strongest typhoons in the world. While early evacuation minimized loss of lives there was massive destruction - ripping off roofs, taking out power lines, damaging buildings and homes. Flood water reached roof tops; many families were left with

nothing but clothes on their back. The successive typhoons and devastation created a double whammy with the ongoing COVID-19 health emergency.

Cancer Warriors Foundation, a CCI member in the Philippines, approached CCI for help. Once again, in the spirit of solidarity, as in the Nepal earthquakes, CCI Asia reached out to other members for support. A total of EUR3,700 from 5 CCI Asia members were raised. This enabled CWF to provide support for rebuilding destroyed/damaged homes, nutrition / food support and more importantly support to continue treatment and maintenance medications for kids with cancer under the care of Cancer Warriors Foundation. Asian Childrens Cancer League (ACCL) of Japan who had previously visited CWF also provided direct family support.



7.6. GOLD SEPTEMBER

AFRICA

Kayula Childhood Cancer Foundation - Zâmbia

In Zambia due to the Corona Virus last year during the government's lockdown we were only able to conduct two activities regarding childhood cancer.

In September for the American Childhood Cancer month we launched the Twenty Kwacha Campaign on two local radio stations as well as two Television stations. During these interviews a lot of awareness on childhood cancer was done. As Kayula Childhood Cancer Foundation, we have received a lot of interest in the organisation as well as a number of donors.

In December 2020 we also had a virtual workout session that was conducted by five local trainers at no cost to us. It was conducted during the week of christmas.

EUROPE

Childhood Cancer Awareness Month 2020

September is the time to raise awareness for children and adolescents affected by cancer and make the meaning of the gold ribbon as the symbol of Childhood Cancer known to the world. CCI Europe had a pleasure to organize the Childhood Cancer Awareness Campaign, together with SIOP Europe and PanCare. Historical and public building in the member-countries lit up gold in support of children suffering from and treated for cancer.

The European Parliament illuminated its building in Brussels with golden light and thus joined the Golden September campaign and support our initiatives.



7.7. PARTNERSHIPS

ASIA

Myanmar - Nutrition program

The nutrition program in Yangon Children's Hospital was initiated in late 2018 and kicked off in 2019. The collaborating partners of the program are CCI, Boston Children's Hospital, and Cankids...Kidscan. In 2020 CCI representatives paid 2 visits to Myanmar:

- January 2020, Carmen Auste, CCI and Nandita Joshi, Cankids together with Erin Gordon, Boston Children's Hospital were in Yangon for the 3-day comprehensive Nutrition Champion Training.
- February 2020, Benson Pau stopping by Yangon and Mandalay on return from Europe to follow up the nutrition program as well as parent support group development in both Yangon Children's Hospital and Mandalay Children's Hospital.

Here are some updates of the nutrition program in 2020:

- 1 full time nutritionist has been employed and his salary was sponsored by CCI.
- 595 children received formal nutrition evaluation.
- 6 hands-on nursing training sessions and 3 hospital wide nursing nutrition lectures.
- 7 care giver education sessions and 3-day comprehensive Nutrition Champion Training.
- Ongoing nursing training and parent education conducted regularly by nutritionist.



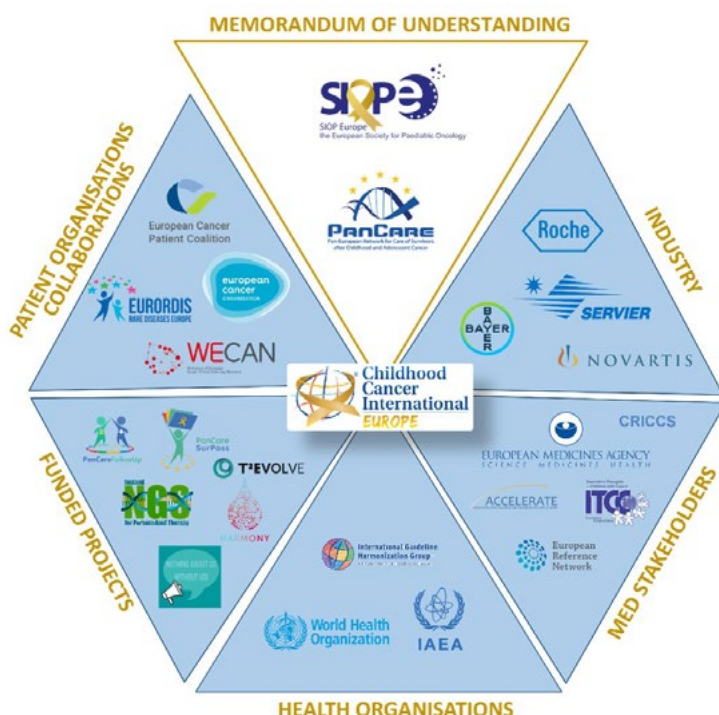
Webinar series of Managing Challenge and Stress during the Pandemic by Sarawak Children’s Cancer Society with CCI Asia region participation

The Covid-19 pandemic has brought to member organizations with it a multitude of challenges. For childhood cancer patients and survivors, the pandemic has exacerbated their anxiety and stress levels. Therefore, Sarawak Children’s Cancer Society hosted a series of virtual meet ups in June 2020 and had the privilege of inviting speaker Mr Michael Teoh of a renowned training company, Thriving Talents in Malaysia, to host 3 talks for Asia: to overcome the challenge of COVID-19 for fundraising, stress management for care takers, and stress management for adolescent survivors. Participants from diverse countries in Asia attended the interesting and participatory webinars with good wisdom learned.

EUROPE

CCI Europe’s collaborations and involvement in projects

In order to ensure the best possible care for children, adolescents and young adults with cancer we are in partnership with several European organisations. With SIOP Europe and PanCare, CCI Europe has a Memorandum of Understanding. We are also keen to advance research and foster collaboration. Therefore, CCI Europe is included in several EU funded projects.



7.8. RESEARCH

GLOBAL

ACCELERATE Innovation for Children and Adolescents with Cancer

AIM: to accelerate innovation in drug development for children and adolescents with cancer

The ACCELERATE international platform (<https://www.accelerate-platform.org/>) provides a transparent forum to discuss and address, in a timely fashion, overarching issues in the development of innovative anticancer medicines for children and adolescents with cancer. The ultimate goal is improvement in outcomes for children and adolescents with cancer. Patients and parents organisations, academic paediatric oncologists and haematologists, researchers, representatives from biopharma companies, regulatory networks and health technology assessment authorities are all equal members of ACCELERATE.

In June 2018, the ACCELERATE platform was reorganised to strengthen international cooperation in order to improve global development of new paediatric oncology drugs.

CCI is an active partner in ACCELERATE, a member of the Steering Committee and works in several Working Groups.

Why ACCELERATE?

Despite major progress over the last 50 years cancer remains the most common cause of death by disease beyond the age of one.

Recently, there have been major breakthroughs in understanding cancer and developing many innovative effective therapies for adults. However, in paediatric oncology, needs are far from being addressed with too many developments of relevant oncology drugs in children being waived or significantly delayed.

Therefore, there is a need to accelerate the process of evaluating innovative therapies and introducing them in standard cancer care in children and adolescents.

How TO ACCELERATE?

Working Groups are composed of representatives of the 4 stakeholders (parent's organisations, academia, pharmaceutical companies and regulatory bodies) and any other stakeholder on an ad hoc basis. The ACCELERATE platform explores the current situation, identifies bottlenecks and hurdles and makes proposals to improve the development of anticancer drugs in the paediatric and adolescents population.

The work performed and the results achieved by the ACCELERATE platform working groups are published in peer reviewed journals.

Paediatric Strategy Forums are multistakeholder meetings to discuss the strategy of new drug development in a given paediatric malignancy or the development of a class of compounds with regards to their Mechanism of Action. These are scientific meetings aimed at facilitating prioritisation in order to better meet the needs of patients and to increase feasibility of paediatric developments.

The ACCELERATE Annual Conference is a forum for discussion, sharing, networking and facilitating the buy-in by all stakeholders. It is the occasion when progress is monitored, proposals are implemented and new areas of improvement are identified.



7.9 MISCELLANEOUS

CANADA



For detailed information visit:

www.kidscancercare.ab.ca/annual-report-2021/assets/pdfs/KCCFA-2020-2021-Highlights.pdf

OCEANIA

Care, treatments and support for all childhood cancer patients in our region has continued during the current ongoing pandemic. Due to the strict lockdown relegations in all our area, we have not been able to do any group work.

Northern Alberta - Kids With Cancer Society

Due to COVID 19 the way that the Kids with Cancer Society conducts and delivers programs has drastically changed. Unfortunately, due to hospital restrictions we no longer have presence at the hospital. Many of our program such as counselling support, educational programs, and general support programs have either been cancelled completely or offered virtually.

We have experienced a surge in our requests for financial support as many of our family's employment status has been impacted by COVID. In addition, requests for therapy have also increased.

Our support of research continues, including support of clinical trials.

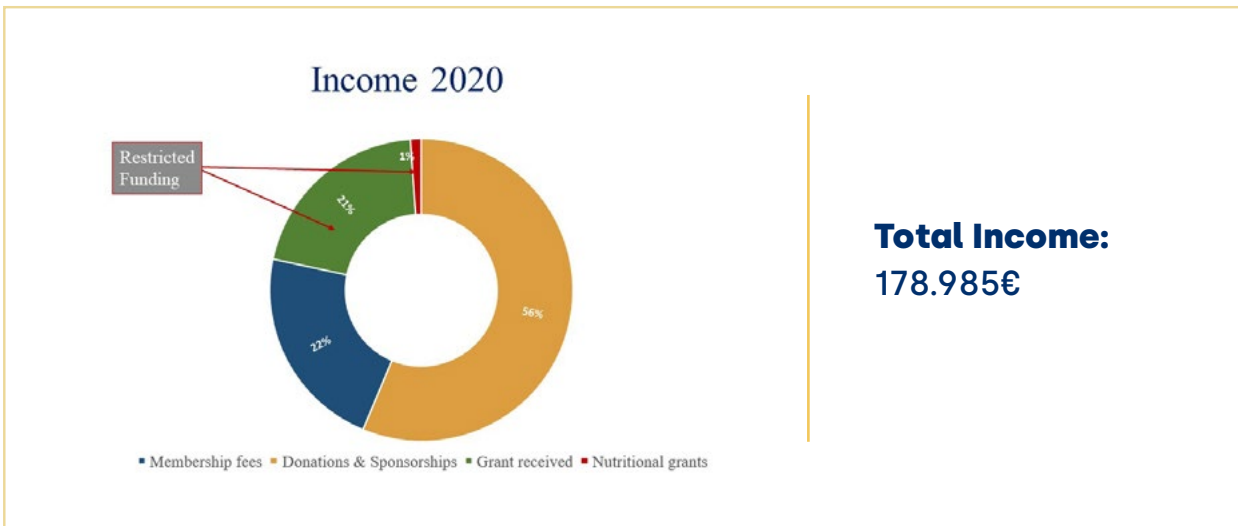
8. Financial Review



The two graphs below provide a general idea of the state of our finances for the year ended the 31st of December 2020.

Regarding the **Income**, the **Donations & Sponsorship** represent around 100.000€ and the **Membership Fees** represent almost 40.000€, slightly less (about 4.000€) than in the previous year.

As for the **Costs**, it should be highlighted that the **Program Costs** represent approx.. 150.000€.



For the complete financial reports click here: <https://www.childhood-cancerinternational.org/about-cci/our-impact/>



Learn more about us

www.childhoodcancerinternational.org

Address

CCI Head Office
Kraijenhoffstraat 137A,
1018RG Amsterdam,
The Netherlands

Social media

[/childhoodcancerinternational](#)

[/internationalchildhoodcancerday](#)

Email us:

headoffice@cci.care