

Welcome

Welcome to the CCI Asia newsletter. This newsletter will keep you informed about events and activities happening in the CCI team and all over Asia. We will also highlight the successful cooperations, participations and initiatives of the CCI member organization.

CCI has always been about generating creative, constructive and encouraging methods to provide mental and emotional support to the children and young adolescents affected by cancer.

The CCI organization, with the help of its members, promotes fights for the rights of children / adolescents with cancer and also confronts discrimination and prejudice.

We are hoping that these amazing stories from all around Asia will inspire and motivate you to take action, as well as inspire you to search for new and innovating ways to help out the kids with cancer, the survivors and all their loved ones. We invite you to get familiar with the CCI organization and start working with CCI in your country. As long as we stand together, hope will never die!



Editorial Team

Bindu Nair (AROH-Giving Hope Managing Trustee, India), **Roula Farah** (CHANCE Association, President, Lebanon)

MESSAGE OF CCI PRESIDENT



Dear CCI Asia members and friends,

Welcome to CCI-Asia's newsletter! As 2019 comes to an end and we look forward to 2020, the CCI Board and I are grateful for the CCI-Asia Regional Committee and the enormous work that continues to be done daily by each and every one of you. It is through the passion and compassion of people like you, who have "walked this walk" that families are able to receive the support that they need when they learn the devastating news that their children have been diagnosed with cancer. This newsletter will give you the opportunity to share ideas and successes together so that the strengths of each other can be used to collaboratively meet the needs of the families of children with cancer in Asia.

As of January 2018, CCI has been in official relations with the World Health Organization (WHO). As we continue into our third year of collaborative work towards the global goal that 60% of the world's children with cancer are cured, I encourage you to build on your relationships with the three WHO Regional offices that serve the Asia-Pacific region: East Mediterranean (EMRO), South-East Asia (SEARO) and West Pacific (WPRO) offices. CCI's official relationship provides you with the opportunity to collaborate with your regional WHO office and to work with governments to build upon the needs of your regions. Unity builds strength and where there is teamwork and collaboration towards a common goal, wonderful things can happen.

The new year brings us together **on February 15th, International Childhood Cancer Day, as we raise our voices in support of #nomoreborders for childhood cancer.** The global disparity of childhood cancer survival rates is unacceptable. As a global voice on ICCD, we have the opportunity to let the world know that there should be #nomoreborders for childhood cancer treatment and cures! Children with cancer have a human right to treatment and hope for a cure regardless where they live in the world. Access to cancer medicines, treatment facilities, financial and emotional support are essential for all children being treated for this disease. I encourage you to utilize the materials that have been developed for ICCD and join the global voice to let the world know that childhood cancer disparity is not acceptable and that CCI-Asia's Regional Committee and its members are working together to ensure equal access to a hope for a cure for all children.

I also invite all of you to mark your calendars and watch for future announcements about **the 2020 SIOP-CCI annual Congress taking place October 14th – 17th in Ottawa, Canada. As in Lyon, the CCI gala networking dinner will take place the evening of October 13th.** I look forward to seeing many of you again and looking forward to hearing more of the work being done in Asia!

Finally, I encourage you to submit your reports to the CCI-Asia Regional Committee on the successes of 2019 so that we can incorporate them into the CCI 2019 Annual report. We are so proud of the work being done around the world and invite you to join with us as we celebrate those global successes.

Wishing you the best for 2020!

A handwritten signature in black ink that reads "Ruth Hoffman".

Ruth Hoffman, President and the CCI Board of Trustees

MESSAGE OF CCI ASIA HEAD



Dear CCI Asia members and friends,

We are very excited to have the debut of CCI Asia Newsletter. Thank you to members sharing their achievement/work/program and the coordination of the Editorial team to make this first edition happen. The Editorial team plan to have biannual Asia newsletter together with FB and IG social media CCI Asia news as well. Stay tuned.

Asia, with over 59% of world population, will need a big team of like-minded people working hand in hand to support childhood cancer improvement in the region. Much appreciated to all the Asia Regional Committee Members for their commitment and tireless effort in supporting the childhood cancer work in Asia.

Most of you know that World Health Organization launched a landmark Global Initiative for Childhood Cancer in September 2018 aiming in reaching at least a 60% survival rate for children with cancer and reduce suffering for all by 2030. CCI are working closely with WHO, St Jude Global, SIOP and other international stakeholders in the global level.

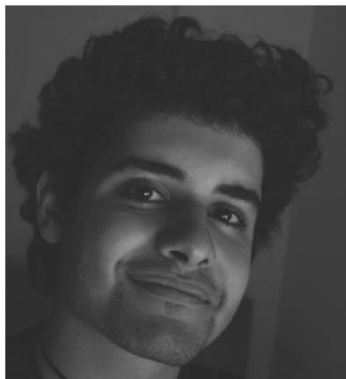
It is a challenge and opportunity for CCI Asia to gear up and engage in the Global Initiative for Childhood Cancer in the 3 WHO region: East Mediterranean (EMRO), South-East Asia (SEARO), West Pacific (WPRO). We look forward to engagement of all members to take this opportunity to advocate for the improvement of childhood cancer plan and services regionally and nationally.

If anyone from your organization are interested to commit your time and experience for the meaningful work, please do not hesitate to reach out to me.

A handwritten signature in black ink that reads "Benson Pau". The signature is written in a cursive, flowing style.

Benson Pau, Head of CCI Asia Committee

SURVIVOR ACTIVITIES / STORIES



"You have cancer". I never thought that one day "you" would be referring to me. My name is Cesar and I was diagnosed with Hodgkin's Lymphoma at the age of 15.

It's never easy to hear the doctor telling you that you have cancer. My heart was broken into pieces that day. I met Dr. Roula Farah a few days later, and that's where the journey began. I put all my faith in my doctor and started chemotherapy. Those were the 7 most life-changing months of my life. Of course, there were a lot of hard times and shocking moments such as experiencing hair loss, nausea, loss of appetite, pain, depression, etc... But thanks to everyone that supported me, I got over every problem that stood in my way.

Cancer's been a very hard and difficult experience, however, I am thankful for it because it taught me to enjoy every single second I'm alive and present on this beautiful earth. Cancer made me stronger, wiser, and shaped me into the man I am today. I wouldn't be writing this testimony if it wasn't thanks to Dr. Roula Farah, CHANCE Association, the residents, nurses, doctors at LAUMC-Rizk Hospital in Beirut, Lebanon that always stood beside me in times of sorrow. They are the real everyday heroes, and I'll be forever grateful to them.

INSPIRATIONAL QUOTES

«Carefully watch your thoughts, for they become your words. Manage and watch your words, for they will become your actions. Consider and judge your actions, for they have become your habits. Acknowledge and watch your habits, for they shall become your value. Understand and embrace your values, for they become your destiny.» Mahatma Gandhi

CCI ASIA MEMBER ACTIVITIES



ASHIC, FOUNDATION FOR CHILDHOOD CANCER, BANGLADESH

"ASHIC MOBILE PEDIATRIC PALLIATIVE CARE CLINIC (MOBILE PPCC)"

ASHIC, Foundation for Childhood Cancer emerged in 1994 as the first NGO for Childhood Cancer in Bangladesh. Since inception, ASHIC has worked with thousands of cancer patients/families. One of our major programs is to improve the quality of life for the terminally ill palliative cancer children.

Our latest addition in our portfolio of programs is the ASHIC Mobile Pediatric Palliative Care Clinic (Mobile PPCC), which is an Ambulance service. With support from my daughter Ms. Maheen Hamid, who has been active with ASHIC and its strategic direction from the beginning, we have received a grant of USD 50,000 from NVIDIA, a U.S. technology company headquartered in Silicon Valley, to pioneer the first Pediatric Palliative

Mobile Clinic offering transportation services and palliative care to an estimated 600 children in rural areas for a period of 24 months. Under this program:

- Terminally ill cancer children will be transported back to their villages after they receive palliative care at ASHIC Palliative Care Unit (PCU) in Dhaka.
- During off duty period the Ambulance service will be used for transporting the patients to their treatment hospitals in Dhaka from ASHIC PCU or bring them to PCU from their residences at Dhaka.
- Offer to transport the deceased to their village homes, which was done earlier through rental services

When the ASHIC Mobile PPCC is in the various rural locales, ASHIC staff arranges for simple mini training sessions on palliative care to medical professionals in the area. This outreach helps to spread awareness in the community, while providing a touchpoint for needy families in remote areas.

In this awareness campaign for palliative care, ASHIC has plans to reach out to twenty-four districts of Bangladesh. Awareness workshops are underway in some remote areas of Bangladesh and the project has already had positive impacts in those communities.



CCI ASIA MEMBER ACTIVITIES



CHANCE (CHILDREN AGAINST CANCER) ASSOCIATION, LEBANON

“RIBBONS OF HOPE”

Because early diagnosis saves lives, CHANCE (CHildren AgaiNst CancEr) Association based in Lebanon launched in several schools a nationwide campaign entitled «Ribbons of Hope» to raise awareness among parents regarding the early warning signs of childhood cancer. Such initiative is a first in Lebanon. The colorful awareness cards distributed to parents accompanied by creative fun activities around the yellow ribbon with the children in their classrooms had an incredibly great impact nationally in transmitting smoothly the message of hope and educating the families about the presenting symptoms of childhood cancer.

Moreover, and due to the success of the initial pilot phase in 20 schools reaching 10,000 families, the Ministry of Education decided to embrace it as a mandatory campaign in 1,200 public schools and a recommendation to be implemented in all private schools. CHANCE president and coordinators conducted training sessions to school teachers and supervisors at the Ministry of Education.

Finally, on World Cancer Day in 2020, we are planning a Press Conference bringing in representatives of ministries of Health, Culture and Education, media representatives, schools, doctors, hospitals, and influencers. The objective is to discuss the burden and warning signs of cancer, the role of schools in early detection and the impact of the campaign in Lebanon.

CHANCE association has been active in Lebanon for 17 years providing the opportunity for each child with Cancer and a Blood Disorder to obtain the best medical care and be cured.



CCI ASIA MEMBER ACTIVITIES



**Children's
Cancer
Foundation**

CHILDREN'S CANCER FOUNDATION (CCF), SINGAPORE

"ANIMAL-ASSISTED INTERVENTION AT CCF!"

Animal-Assisted Intervention (AAI) programme is the latest therapy service offered by Children's Cancer Foundation (CCF) for children and families affected by cancer. Led by CCF's Principal Social Worker, Fion Yip, who is certified in Play Therapy and Animal Assisted Therapy, AAI comprises Animal-Assisted Activity (AAA) and Animal-Assisted Therapy (AAT) sessions for individuals and groups.

AAA provides opportunities for motivation, education, or recreation to enhance the quality of life of our beneficiaries through human-animal interactions. The inaugural AAA session was launched in December last year and participants learnt about AAT and AAA, and the differences between the approaches. Seven volunteer dog handlers and their pooches volunteered their weekend to spend time with our beneficiaries. Besides patting and playing with the dogs, they participated in games such as "Blindfold Picasso" where the child had to feel a part of the dog while being blindfolded and draw what they felt. Other games included an "Obstacle Course" where the caregivers had to set up obstacles using chairs, hula hoops and cones for their child to navigate the dogs through.

AAT is directed and delivered by a formally trained therapist with specific goals for children impacted by cancer to enhance their emotional well-being. Since April 2019, AAT was offered as part of individual therapy. CCF will also be introducing group AAT sessions in the last quarter of 2019.



CCI ASIA MEMBER ACTIVITIES



BASMA, SYRIA

"BASMA, AN NGO-BASED PEDIATRIC ONCOLOGY UNIT, IS EXPANDING TO SERVE MORE SYRIAN CHILDREN WITH CANCER AFTER END OF WAR IN DAMASCUS"

Despite all the critical financial and security-related circumstances, BASMA has never closed its doors to serve Syrian children with cancer during the most intense period of Syrian war between 2012 and 2018. As war had come to an end in Damascus, the -18bed pediatric oncology unit was not able to accommodate the high number of new admissions from Damascus and all other Syrian cities, from north to south.

Because of the high demand, we decided to expand our capacity to 36 inpatient beds, 13 outpatient beds, in addition to a new pediatric intensive care service.

In an agreement with the Governmental Oncology Hospital, we added a new floor to our unit. The floor needed renovation because it was significantly affected by the close by military operations.

Renovation has started in the last few weeks of 2018. We are currently at the latest stages of the work. The new unit will be ready in few weeks.

The expanded unit will need enough staff to make it operational. For this purpose, we recruited a new medical director, trained outside the country, in a St Jude accredited training program. In addition, we are currently recruiting new physicians and nurses.

We hope that the expanded unit will double our capacity and our ability to enroll more patients to treat them in the appropriate setting in our country



CCI ASIA MEMBER ACTIVITIES



ASIAN CHILDREN'S CARE LEAGUE (ACCL), JAPAN

EXTRACT FROM VIET NAM NEWS ON 28 NOVEMBER, 2019 "JAPANESE WOMAN CARES FOR CHILDREN CANCER PATIENTS IN HUẾ"

Over 20 years ago, a Japanese woman visited the central city of Huế and fell in love with the place. She has returned many times to support children fighting cancer. Kazuyo Watanabe is now a familiar face for children their parents at the Paediatrics Centre at Huế Central Hospital. She visits Huế four times a year, and spends most of her time with patients.

"My wish is for as many children as possible with relapse and refractory problems to be saved with advanced treatment; we have set up a transplant unit on the fifth floor of the hospital," she told *Việt Nam News*. Total funding for the new facilities has reached VNĐ8.5 billion (US\$366 thousand), contributed by Japan Asia Group Limited and individuals and agencies in Japan.

As the founder of the Asian Children's Care League (ACCL), a non-profit organisation in Japan, Watanabe chose to support children with cancer and their families in Asia, starting in Huế. "The reason I chose Huế is because I lived there for a year when I was involved in supporting street children back in 1995, where many people suffer economic hardships," she explained.

Professor Phạm Như Hiệp, director of the hospital, said "Her restless efforts have resulted in increasing the rate of child patients who live on for more than five years without any problem to 50 per cent, and the ratio of children with cancer who survive to 70 per cent,".

Watanabe initiated the House of Hope in January 2016 for children and their parents to have a "home away from home to provide a safe place to cook nutritious and delicious meals, rest and spend time with their families." The project has received donations from domestic and foreign individuals and agencies.

"Cancer is not only a health issue, because there are social issues involved, which led us to a 'holistic-dynamic-sustainable-harmonic approach' to cancer care," she said.

Watanabe said in country like Việt Nam, late diagnosis and presentation of cancer remained a huge issue, so outreach projects from central hospitals have been launched to emphasize the need for early detection and referral. She said networking with local hospitals was essential for treating the maximum number of children as possible in the region.

Watanabe said the foundation had faced a lot of difficulties such as financial and emotional burdens on families, different habits, a shortage of medical staff; lack of facilities and medical equipment and a public stigma about cancer. "Key to tackling these challenges was connecting the dots of human resources, materials, financial sources, information and time, in an open and cross-disciplinary manner," she said.

Many children patients and their parents call her "Japanese mother".

“The greatest happiness I have is meeting the volunteers who help them,” she said. “They are my source of inspiration. Devoted medical staff, enthusiastic student volunteers, kind supporters and lovely children. We are ‘One Family’ together.”

She said she is happy to see many survivors of childhood cancer grow up with big smiles on their faces. She will also never forget the precious lives and smiles of the children who didn't make it. She keeps in touch with their families and tries to visit them as often as possible.

Watanabe stressed that 'bottom-up' grassroots activities could make changes, but to achieve a maximum impact to save as many children as possible, a “top-down” Government involvement was needed. It was very important to have the tools to convince the Government through international co-ordination of advocacy, research and policy, she said.

Watanabe said Huế was a beautiful city with warm people. She call the city her second home and treats the people like her relatives.

She has just received the Japanese Foreign Minister’s Commendation for outstanding achievements in the promotion of mutual understanding between Japan and Việt Nam. She has also received the Medal of People’s Health from the Vietnamese Government for her contributions to the development of childhood cancer treatment and care in Việt Nam.



Kazuyo Watanabe (centre) with cancer patients at Huế Central Hospital. Photos courtesy of Kazuyo Watanabe



Kazuyo Watanabe (first right) makes a speech at a ceremony at the Faculty of Paediatric Oncology-Hematology at Huế Central Hospital.



Kazuyo Watanabe plays with the children at the Paediatrics Centre.

CCI ASIA MEMBER ACTIVITIES



MAHAK, IRAN

"THE 5TH INTERNATIONAL CONGRESS ON CSR"

The 5th International Congress on Corporate Social Responsibility was held on the occasion of ICCD on 25 February 2019 with themes of "Planning Models, Implementation Models and Reporting Standards" at MAHAK.

This congress was held with the presence of more than 300 participants along with various professionals as speakers from well-known organizations and entities including the International Project Management Association (IPMA), World Health Organization (WHO), UN Global Compact, UNICEF, Hoffmann-La Roche Ltd. and different universities such as HTW Berlin, Amir Kabir University of Technology as well as Iran-Switzerland Chamber of Commerce.

In this congress, Arasb Ahmadian, the CEO of MAHAK presented a comprehensive report on the activities of MAHAK in the field of CSR and stated: "One of the principles of MAHAK's mission is promoting the supreme concept of supporting the fellow beings which is expected to develop a new concept of corporate philanthropy.»

In addition, the following panels were held in the course of this congress:

Planning Models: moderated by IPMA representative, focused on the importance of project management, social responsibility and its planning and its relation to the NGOs from the academicians' points of view.

Implementation Models: the combination of an economic entity, UNICEF and an entrepreneur university as the members, in which social responsibility was addressed in specialized fields and different experiences and points of view was shared accordingly.

Moreover, Saideh Ghods, founder of MAHAK and a member of Asia Regional Committee of CCI appreciated all the participants who aimed to fulfill their social responsibility having the concern of supporting their fellow beings and hoped to witness successful utilization of project management competency in obviating social issue.

As it is mentioned in the congress statement, MAHAK considers the 5th International CSR Congress as the last step of its mission in realization of this concept in the society and believes that all its efforts during the last 12 years have bore fruit. Accordingly, MAHAK commits itself to deliver its first report based on the Global Reporting Initiatives (GRI) standards to fulfill its social responsibility.



CCI MEETING IN LYON

The Annual Congress of Childhood Cancer International was held from 23-26 October 2019, at Lyon Convention Center in France (in conjunction with the 51st Congress of the International Society of Pediatric Oncology). A big part of the 2019 conference success was thanks to the great work of our UNAPECLE friends for over a year. (Union Nationale des Associations de Parents d'Enfants atteints de Cancer ou LEucémie).

In four intense days of work, experiences, knowledge and new ties were created among CCI members and delegates to improve the quality of life of childhood cancer. Multi-disciplinary health care professionals involved in the care of children and teenagers with cancer and their parents coming from all around the world attended the meeting.

Dr. Andre Ilbawi confirmed that the relationship with CCI is needed and appreciated by the World Health Organization. Progress is being made in a global advocacy campaign: regional dialogues have been generated and country actions with accountability have been promoted and implemented.

During the conference, survivors from all the continents shared their experiences and realities of their countries and the new International Childhood Cancer Day campaign was shown. On February 15 we will say together that «Childhood cancer knows no borders, neither should the cure»

Many important topics were discussed for the survivors, families and CCI organizations from all over the world, such as:

- Discovering Therapeutic Massage, by La Roche Posay Foundation
- Cancer Registries in LMIC
- Ethics and Biobanks
- Parents and Patients Priorities, Involvement and Support
- Survivorship
- Risk Factors for Childhood and Adolescents Cancers
- Pain Management
- Improving Care and Quality of Life

Moreover, the CCI Asia Committee had several meetings and discussed their upcoming projects to protect the rights of families and children with cancer all over Asia, improve cure rates and enhance collaboration and partnerships among countries.



UPCOMING EVENTS

1) 13th CCI Asia Conference, Mumbai, India, 27-28 March, 2020

Venue: Hotel Taj Lands End, Mumbai, India

Online registration: <https://in.eregnow.com/ticketing/register/SIOP2020>

Important date to be remembered:

Global Initiative for Childhood Cancer : 1st Asia Stakeholders Workshop

Date: 26 March 2020 Time: 12:00 to 17:00

Enquiry: Local: cciasia2020@gmail.com International: Benson.pau@Pkwfoundation.org

CCI Asia Survivor Track:

Date: 26-27 March 2020, free registration fee, Survivor Track Registration,

Enquiry: Local: cciasia2020@gmail.com International : connie.yu@pkwfoundation.org

2)



3)



15 February

#nomoreborders #cureall

4) CCI International Conference will take place in Ottawa, Canada, from 14th to 17th October, 2020. Save the Date



CCI ASIA REGIONAL COMMITTEE

CCI Asia Regional Committee	
Head of Committee	Benson Pau, Pau Kwong Wun Charitable Foundation, Hong Kong, China
1. Capacity Development	
a) Regional Conference	Gary Ho, Sarawak Children's Cancer Society, Malaysia
b) Develop parent group in Asia	Carmen Auste, Cancer Warriors Foundation, Philippines Manal Elewah, Art2Care, Egypt
c) Survivor group development	Poonam Bagai, Cankids...Kidscan, India Roula Farah, CHANCE Association, Lebanon
2. Communications & Awareness Building (CCI regional campaigns, newsletter, social media...)	
	Bindu Nair, Aroh-Giving Hope, India Roula Farah, CHANCE Association, Lebanon
3. Finance & Resources Mobilization (funds, resources, grants...)	
	Sawsan Abdul Salam Al Madhi, Friends of Cancer Patients, UAE Poonam Bagai, Cankids...Kidscan, India
4. Membership Development & Data Management (existing/potential member contact, membership fee...)	
	Ira Soelistyo, Yayasan Kasih Anak Kanker Indonesia, Indonesia Kohsuke Yamashita, Children's Cancer Association of Japan, Japan
5. Research (useful research publications to share...)	
	Roula Farah, CHANCE Association, Lebanon Saideh Ghods, MAHAK, Iran
6. Strategic Partnership & Advocacy	
	Carmen Auste, Cancer Warriors Foundation, Philippines Kazuyo Watanabe, Asian Children's Care Leggue, Japan



*May this festive season sparkle and shine,
may all of your wishes
and dreams come true,
and may you feel this happiness
all year round.*



Armenia



Azerbaijan



Bangladesh



China



India



Indonesia



Iran



Iraq



Israel



Japan



Jordan



Lebanon



Malaysia



Nepal



Philippines



Russia



Singapore



South Korea



Syria



Thailand



UAE



Vietnam