



About the Cover:

In artist own words:- "I have painted this painting to show what a painful and extreme journey cancer treatment is. We all need love care and happiness to heal it... Together we can do anything."

About the Artist:

About the artist : 14 year old Madhurima Baidya is a multitalented young person and prolific painter.



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Immediate Past President
Dr. Akira Nakagawara

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Dr. Rashmi Dalvi

Newsletter Editor
Dr. Maya Prasad



Dr Maya Prasad, M.D.

Associate Professor, Paediatric Oncology,
Tata Memorial Hospital, Mumbai

Dear Friends and Colleagues,

It gives us great pleasure to bring you the first issue of the newsletter for 2018. This year promises to be an eventful one for SIOP ASIA. As we know, the annual congress of SIOP returns to Asia after 5 years . The 50th Annual SIOP congress promises an outstanding scientific programme in the historic and amazingly beautiful Kyoto. As Dr Nakagawara reports, a record number of abstracts have been submitted this year, with an encouraging increase from Asia. Following elections held last year, Dr. Rashmi Dalvi is now president-elect of SIOP Asia and will take up the presidency at the Kyoto Congress.

As always, this newsletter also carries reports from scientific as well as CCI events from the past few months. Dr Li's message carries the link to the online version of the cancer resources directory Asia as well as information about SIOP Asia congress 2019 to be held at Abu Dhabi and the bidding process for SIOP Asia congress 2020.

Once again, inviting contributions for the newsletter in the form of reports/photographs from scientific or social events, as well as personal perspectives and/or poetry/art contributed by health professionals and patients.

Best Wishes

Message from the Continental President



Dr. Chi-kong Li

Professor, Department of Paediatrics,
The Chinese University of Hong Kong,
Prince of Wales Hospital.

Message from the President

We held the Annual General Meeting on 13 October 2017 at Marriott Wardman Park Hotel, Washington during the SIOP 2017 Congress. Over 30 members attended the meeting and also had representation from SIOP Board - Dr. Paul Rogers, Secretary General of SIOP with colleagues from Childhood Cancer International (CCI) also joining the meeting. Dr. Eman Al Shamsi presented the proposal of scientific program of SIOP Asia 2019. The congress will be held at the Abu Dhabi National Exhibition Centre (ADNEC) on 5-7 April 2019, with a pre-congress workshop on 4 April 2019. The members actively discussed about the format of the congress and gave positive feedback to the Local Organising Committee. Finally the AGM confirmed the SIOP Asia to be held at Abu Dhabi. We look forward seeing all of you at the next SIOP Asia Congress in Abu Dhabi as we will skip Asia congress in 2018, and Kyoto will host the main SIOP congress in November 2018.

It is time to plan for the SIOP Asia 2020 congress. According to our endorsed Bidding rules, members with interest to host the SIOP Asia 2020 congress should submit a bidding before the AGM and members will select the venue at the AGM. Please send the bidding application to me before 31 July 2018, and then the bidding team will make a presentation in the AGM and answer questions from the members. One of the key features of SIOP Asia is to attract more local attendance around the region of the hosting city. Travelling to overseas conference is still expensive and is always not feasible for young colleagues, the Continental congress serve the purpose of bringing updates of childhood cancer to hosting country and nearby region.

As you know, WHO has now granted SIOP the status of non-state actor on February 08, 2018. With the great effort of Dr. Gabriele Calaminus and her team, SIOP is now getting the official relations with WHO. This new mandate provides SIOP with unique opportunities, privileges and responsibilities. SIOP will have a presence at WHO meetings and collaborate within the rich network of WHO partners. We believe SIOP will gain more strength as advocacy for childhood cancer, and able to liaise with various government to promote the cancer care for children.

February 15, 2018, International Childhood Cancer Day (ICCD) is celebrated around the world. ICCD is a day founded by Childhood Cancer International (CCI), a global network of 188-member organizations in 96 countries. Every year many countries organised ICCD activities, and instilling hope for all children and adolescents diagnosed with cancer in the world. Both SIOP and CCI is committed to improve childhood cancer care globally and they share a long and fruitful synergistic cooperation. In this issue of Newsletter, we will have messages from various countries sharing the activities of ICCD.

SIOP Asia is also collaborating with CCI Asia chapter to produce a directory on the national societies and non-government organisations for children cancer. The first issue is now available at the SIOP Asia website, http://siop-online.org/wp-content/uploads/2017/09/Childhood-Cancer-Resources-Directory-Asia_final-v170908.pdf. We need your support to provide information of your national society or NGOs to make this directory comprehensive, please send information to me.

Last but not the least, the new President Elect of Asia SIOP was formally announced in the SIOP Congress at Washington last October. Welcome Dr. Rashmi Dalvi from Mumbai as the next President of SIOP Asia!

Chi-kong LI

Continental President, Asia SIOP



Dear Colleagues

As I pen a few thoughts for this Spring issue, I look back to our experiences with the development of Pediatric Oncology in the region: through the trials & tribulations of the late 80s, 90s, to better possibilities of management & outcome now, in nearly two decades of the new millenium. SIO Asia as an organisation provided a wide platform for scientific dialogue between the of excellence of care from "developed" countries and the challenges in "resource restricted" setting; fostering valuable collaborations & twinning .

Asia represents a wide spectrum in health economics, with supergiants in the Far East to low income states in South Asia, and the rest in between, with different levels of development. In improving survival in childhood cancer at all levels of care, the issues at stake in Asia are burden of disease, comorbidities eg. infection & malnutrition, human and financial resource constraints & need for advocacy at governmental levels. Many of the answers need to come from our own data and our population demographic is an asset for clinical research. SIO Asia meetings have promoted exchange of ideas to replicate & expand, successful models and best practices within the region; complemented by involvement of the nursing forum, parent/ survivor groups & support organisations.

May I thank the membership for the support & confidence shown, enabling one to take up this position on the SIO Asia Board. I do look forward to learning from & working with all of you in future. Dr Chi Kong Li and I, we welcome inputs & ideas on how best to use the strength of SIO Asia, to better the cause of childhood cancer care in Asia. Hoping to see many of you at the SIO Asia 2018 in Kyoto!

Dr Rashmi Dalvi

Continental President-Elect SIO Asia

rashmidalvi5@gmail.com

Minutes of 2017 SIOP ASIA Annual general meeting

Date : 13th October 2017

Venue : Washington Room 6, Marriott Wardman Park Hotel, Washington

1. The Continental President Chi-kong Li (CL) welcomed members to the

AGM. CL also welcomed Dr. Paul Rogers, Secretary General of SIOP and colleagues of Childhood Cancer International (CCI) joining the meeting. A total of 30 SIOP Asia members and 3 CCI members attended the meeting.

2. Minutes of 2017 Annual Business Meeting (Bangkok): the minutes had been circulated to members by email and also Newsletter, there was no amendment received, and the minutes were adopted.
3. Dr Panya Seksarn, president of 11th SIOP Asia congress, reported on the Congress. There was a total of 432 attendees at the congress, 315 attending SIOP Asia, of which 146 were overseas participants and 169 from within Thailand. For the CCI conference, there were 117 participants , with 63 overseas attendees who came from over 30 countries. The program consisted of keynote lecture, educational sessions, oral presentations and PODC session. A pre-conference workshop on palliative care was also arranged. There was very good feedback on the conference. CL thanked Dr Seksarn and the local organizing committee for the excellent organization and high quality program.
4. Presentation of bidding on 2019 Asia SIOP Congress: The Local Organizing Committee from United Arab Emirates (UAE) joined the meeting and made a presentation on the proposed program. Dr. Eman Al Shamsi

presented the proposal of scientific program, The congress will be held at the Abu Dhabi National Exhibition Centre (ADNEC) on 5-7 April 2019, with a pre-congress workshop on 4 April 2019. There will be education sessions, oral presentations and poster sessions. A session will be delegated to presentation from Paediatric Oncology East and Mediterranean (POEM) as the regional organization may present topics of regional interest. Members also expressed the opinion of a comprehensive program including surgical oncology, PODC and nursing program. There was suggestion of including more regional or Asia speakers to deliver lectures. CCI colleagues also expressed the intention of organization parallel parents and survivor workshops during the congress. Finally representative from the Abu Dhabi Tourism and Cultural Authority presented the logistic arrangement and traffic options. Colleagues enquired about the flight and ground transport to Abu Dhabi and also the choice of hotels. A range of accommodation cost from 4-5 stars to economic class was suggested by members, in particular members coming from LMIC. There was also suggestion of increasing the number of scholarships to young investigators from LMIC. The LOC would consider the above suggestions and work on the feasible options. After the presentation and discussion, there was no objection from members for Abu Dhabi to host the 12th Asia SIOP Congress in 2019. CL on behalf of SIOP Asia congratulated Abu Dhabi team for the successful bidding of the congress. The Executive Board of SIOP Asia will work closely with LOC on the details of the scientific program, and also report back to SIOP Board._

5. Report on Newsletter of Asia SIOP 2017: Dr. Maya Prasad, editor of Newsletter, could not attend the meeting. CL on behalf of Dr. Prasad reported on the Progress. The Newsletter is produced two times per year, and the work is done on a voluntary basis without funding. Contributions from members are welcome and sharing of the professional and parent/survivor activities in the regions are particular attractive. The newsletter is now distributed by emails to members but sometimes have to be in separate mails due to the big size of the file. A link of the newsletter to Asia SIOP website is also available. CL would like to thank Dr. Prasad for her great contribution in producing the high quality Newsletter.
6. CL Reported that the Booklet on Asian Paediatric Haematology & Oncology Societies and Centres is now produced with contributions from 19 countries and regions. Some countries had both the national societies and the NGOs, while some only had either one of the organization. CL strongly encouraged members to continue the contribution to make this first version complete. The next phase will be contributions from individual treatment centres after vetting by national societies. We aimed at completion of the submission by mid 2018, and then the hard copies of the Booklet will be produced under the support of NSPHO of Russia Federation. The link of the electronic version is now available at the SIOP Asia website:

http://siop-online.org/wp-content/uploads/2017/09/Childhood-Cancer-Resources-Directory-Asia_final-v170908.pdf
7. CL reported that the new category of Asia SIOP Membership, non-voting member, was created last year. Since then there were about 20 applications received and the applications will be endorsed after circulation through the Executive Board of SIOP Asia. Dr. Paul Rogers also elaborated on the new membership fee to be discussed in the General Business Meeting of SIOP one day late. A very low membership fee of 20 Euro will be offered to LMIC, and the members would also receive the electronic copy of PBC with the agreement of Wiley. SIOP would encourage more colleagues to join SIOP. CL welcomed the new arrangement and expressed the hope that more colleagues in Asia will join SIOP, and the non-voting membership of SIOP Asia may serve as an intermediary to introduce SIOP activities to non-members.
8. CL reported that the election for President-elect of Asia continent was successfully conducted, and Dr. Rashmi Dalvi is elected, and the result will be formally announced in the SIOP Annual Business Meeting the day following.
9. Since there will not be SIOP Asia congress in 2018, the next SIOP Asia Annual General Meeting will be held in Kyoto during the SIOP 2018. The bidding for 2020 SIOP Asia will also be opened end of 2017 and to be confirmed at Kyoto meeting in 2018.
10. There being no other business, and the meeting was adjourned at 14:00

Report : SIOP 2017 post-closing session

“Translation of knowledge – An NSPHO and SIOP PODC Review and Discussion”

During the 49th Congress of the International Society of Paediatric Oncology (SIOP) held in Washington October 12-15, 2017 a special post-closing session “Translation of knowledge – An NSPHO and SIOP PODC Review and Discussion” was included in the agenda.

This session attracted participants from various countries in Asia, the Americas, Europe and Africa. The session was chaired by Julia Challinor (the Netherlands), Svetlana Varfolomeeva (Russia), Alan Davidson (South Africa) and Tezer Kutluk (Turkey) and moderated by Carlos Rodriguez-Galindo (USA). Invited talks and a panel discussion were included in the 2 hour and 30 minute session.

The session started with introductory talks from invited leaders Paul Rogers (SIOP Secretary), Tezer Kutluk (UICC past President), Chi Kong Li (SIOP Asia, Continental President) and Alexander Romyantsev (NSPHO President).

The plenary session included the following presentations: “Moving from 5 to 85: Russian unique protocol experience” by Alexander Romyantsev, “LMICs practical guidelines in

pediatric oncology” by Scott Howard, “PODC work with preparation of adopted therapy regimens” by Patricia Alcasabas and Sandra Luna-Fineman, “AHOPCA experience in Central America and the Dominican Republic” by Ligia Fu, “VIVA/SIOP Asia experience” by Catherine Lam (USA), “SIOP African Wilms’ tumor project experience” by Vivian Paintsil, and “NSPHO experience in pediatric oncology” by Kirill Kirgizov.

Various approaches to the treatment of pediatric cancer in LMICs were discussed during the talks and panel discussion. The roles of governmental support and scientific guidance provided by SIOP to achieve success in limited-resource settings were highlighted. Finally, a discussion on the process for developing and selecting the most appropriate resource-adapted treatment protocols followed.

The session was of high interest to the participants, with presentations that shared novel and relevant data. Prof. A. Nakagawara, Local Chair of SIOP 2018, proposed organizing the same session during the Congress in Kyoto.

You can find more photos here: <https://photos.app.goo.gl/BsilGT7dfN47yY1j1>



Glimpses from SIOP Asia 2017, Bangkok



SIOP 2018, Kyoto :

Message from Local Organizing Committee



Dr Akira Nakagawara
Chair, Local Organizing Committee

Dear friends of SIOP,

The SIOP 2018 Congress in Kyoto is coming soon. It will be held in November, 2018, when Kyoto, an ancient capital of Japan with amazing history and wonderful arts, will be covered by beautiful color changes of leaves of the trees in many old temples, mountains and rivers. Our local organizing committee members as well as many other supporters including survivors and volunteers are enthusiastically working for preparation of the congress.

On behalf of the SIOP 2018 Local Organizing Committee, I am pleased to share important congress updates with you.

The abstract submission was closed on April 10th. As the result, it was fantastic that the SIOP office received 1,546 abstracts for the SIOP 2018 congress which is the most largest number in the history of SIOP (as a reference, 1,186 at SIOP 2017 in Washington DC). The no.1 was India, no.2 USA, no. 3 Japan and no. 4 China. The number of abstracts submitted from Asian countries have largely increased this time.

We are currently working on putting together an outstanding scientific programme and look forward to gathering top experts in paediatric oncology all in one place. Exciting highlights include keynote lectures by Dr. Yoshinori Ohsumi, 2016 Nobel Prize Laureate in Physiology or Medicine, and Giorgio Perilongo, Past SIOP President.

Visit the SIOP website, and our social media networks on Facebook and Twitter to get the most recent congress updates. Please feel free to share the links and posts among your professional networks. Thank you for contributing to the success of SIOP's 50th Congress and its vision for a world where no child should die of cancer.

We are really looking forward to seeing you in Kyoto this year.

Sincerely,



siop.kenes.com

Report : Joint meeting of Vietnam-Russia specialists on pediatric oncology and hematology

Joint meeting of Vietnam-Russia specialists on pediatric oncology and hematology was held in Ho Chi Minh city November 13-17, 2017. This meeting was organized by the University of Medicine and Pharmacy at Ho Chi Minh city, Ho Chi Minh city Children Hospitals, The National Society of Pediatric Hematologists (NSPHO) and Oncologists and Dmitry Rogachev National Research Center of Pediatric Hematology, Oncology and Immunology (Moscow, Russia). This meeting became possible after the first contacts between Russian and Vietnamese colleagues during the SIOP Asia Congresses (especially, SIOP Asia 2016).

Vietnamese and Russian pediatric haematologists-oncologists (who is also active in SIOP Asia) participated the meeting – Prof. Svetlana Varfolomeeva, Prof. Thai Nguyen, Prof. Minh Tan Nguyen, Dr. Konstantin Dobrenkov, Dr. Bao Chi Bui, Dr. Kirill Kirgizov and others.

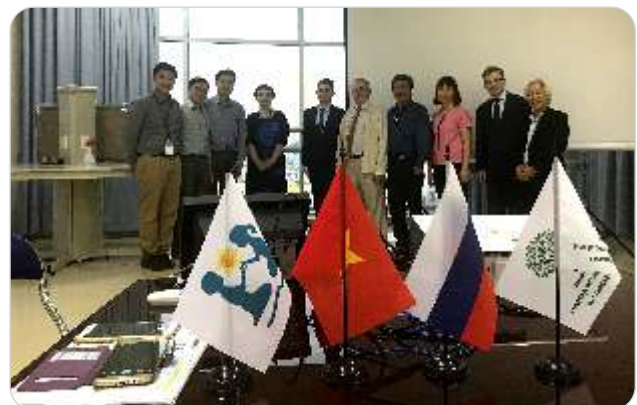
During the meeting colleagues from Vietnam and Russia signed a “Memorandum of Understanding”, visited University and Ho Chi Minh city children’s hospitals. A special part of program was the series of meetings to discuss the prospects of collaboration.

It as decided to continue such Meetings to improve collaboration in research protocols, new technologies (e.g. NGS, etc.), cancer registries building and to establish “Vietnamese-Russian group on pediatric hematology-oncology and immunology”.

Next meeting will be held in Saint-Petersburg during the NSPHO Annual Meeting in April 2018.



MOU signing ceremony



Discussion on prospects

Report : Pediatric Neuro-oncology evolution and future perspective in Pakistan



Naureen Mushtaq
MBBS, MCPS, FCPS
Assistant Professor.
Pediatric Neuro-Oncologist.
Aga Khan University Hospital, Karachi.

Brain tumors are the most common solid neoplasm and leading cause of malignancy related death in children. CNS malignancies represent approximately 16.6% of all childhood malignancies. Children with brain tumors do not have as favorable outcome as non-CNS malignancies nor has their survival dramatically improved in the recent decades, as we did see with other types of cancers. Nearly 88 % of the world's children live in developing countries and 80 % to 90 % of the 250,000 new cases of pediatric cancer each year are diagnosed in a LMIC. In general, pediatric oncology represents a substantial challenge for developing nations due to inadequate access to pediatric oncologists, a shortage of trained experts in pediatric cancer histology and imaging, scarcity of dedicated pediatric cancer units, and inadequate diagnostic and imaging techniques.

Pediatric Neuro-oncology, in particular, depends on large teams of highly specialized individuals, including neuro-oncologists, neurosurgeons, neurologists, radiologists, radiation oncologists, pathologists, palliative care specialists, oncology nurses, physical therapists, occupational therapists, speech therapists, pediatric intensivists, and social workers to establish the correct diagnosis, deliver appropriate and effective treatments, and maximize patient outcomes. There are many obstacles in the development of pediatric oncology programs for LMIC, such as poverty, malnutrition, lack of education, and poor compliance from families. The lack of pediatric oncology specialization and the absence of key leaders in different fields is another major barrier to the progress of this discipline in LMIC. A third impediment is the frequent lack of cross-talks among different disciplines, resulting in delayed and improper referrals that negatively affect the outcome, when treatment requires a multidisciplinary approach

A crucial first step toward establishing neuro-oncology programs in developing nations is to define the need. In Pakistan a population of approximately 20 billion there are very scarce data available for children with brain tumors and Pediatric Neuro-oncology is one the most neglected superspeciality in Pediatric oncology field. We only have two centers across Pakistan who are right now dealing with children of brain tumors. Both centers are located Karachi the biggest city of Pakistan. One is my institute Aga Khan University Hospital and is arguable the only center in the whole country with all the facilities under one roof for managing these critical patients. Approximately 60-70 new children with brain tumors are admitted each year at Aga Khan University Hospital. However, despite being the only center across country we had no multidisciplinary team and lack of expertise in Neuro-oncology before 2014.

To fill this gap we required substantial collaboration between developed and developing nations which was not possible with limited resources available in Pakistan. One successful initiative has been incorporated in various LMIC for other malignancies is twinning program, telemedicine is the most successful component among the rest. As neuro-oncology is a very complex field so it should not be limited to cooperation between pediatric oncologists only, for betterment of management other key members of the team such as neurosurgeons, radiation oncologists, pathologists, and neuroradiologists should be part of this activity to learn in unison. To done that a Twinning program has been started with The Hospital of Sick Children, Toronto with great help from my mentor Dr Eric Bouffet the Division head of Neuro-oncology at Sickkids and his team of world renowned Neuro-oncologist, scientists and neuropathologist Dr Ute Barte, Dr Uri Tabori, Dr Viay Ramaswamy, Dr Annie Huang and Dr Cynthia Hawkins. It later on followed by the first ever Pakistani international videoconference assisted Pediatric Brain Tumor board in June 2014. This is a monthly activity and up till now approximately 208 patients has been discussed in 37 months. Dr Eric Bouffet and his team also helped us characterizing Medulloblastoma molecular subgroups, next generation sequencing, highly specialized molecular markers not available in Pakistan and genetic testing for families with cancer predisposing syndromes. This whole activity helped us immensely to develop a Pediatric Neuro-oncology multidisciplinary team at our institute in 2015. This team includes Neuro-oncologist, Neurosurgeon, neuroradiologist, neuropathologist, radiation oncologist and physiotherapist and any child admitted with a working diagnosis of brain tumor will take over by this team from the start. This activity not only improves the outcome in our patients but now we are in a position of sharing our various data with other centers of Pakistan to help them develop neuro-oncology services in their respected centers. Our vision for future perspective for Pakistan includes the establishment of twinning at a national level with other cities of Pakistan and a Pediatric Neuro-oncology tumor board through cre4kids network.

Hopefully, we will continue to gain ground in Pediatric Neuro-oncology, as advancing technology helps bring health care providers together in developing and developed countries.



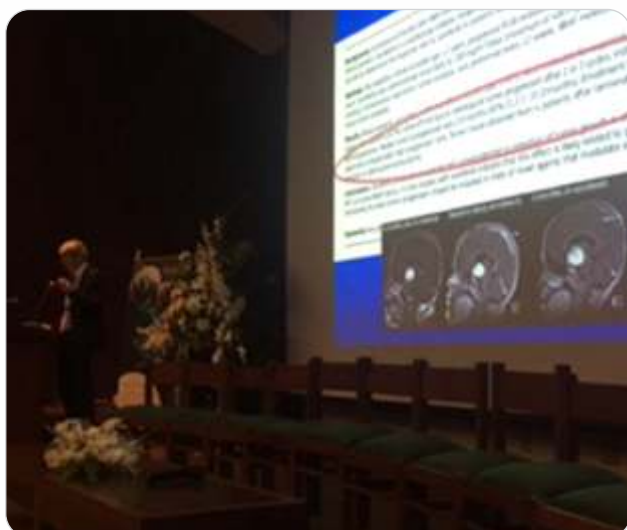
The Sickkids team led by Dr Eric Bouffet, Dr Uri Tabori, Dr Cynthia Hawkins and fellows



The Aga Khan University Hospital team including Neuro-oncologist, Neuro-surgeons, Radiologist, Histopathologist, Radiation Oncologist and fellows.



Last month Dr Eric Bouffet visited Pakistan and conducted a very informative Pediatric Neuro-oncology Outreach Course for Physicians.



Report : 10th International SIOP-PODC International Nutrition Workshop

Venue: Tata Memorial Hospital, Mumbai

Date : 12th -13th January 2018

Organisers

- Co-hosted by SIOP, TMH Mumbai, Sujaya foundation, Cuddles Foundation, CanKids
- Co-Chairs: Amita Trehan, MD; Elena J. Ladas, PhD RD
- Org. Secretaries: Maya Prasad, Shalini Jatia

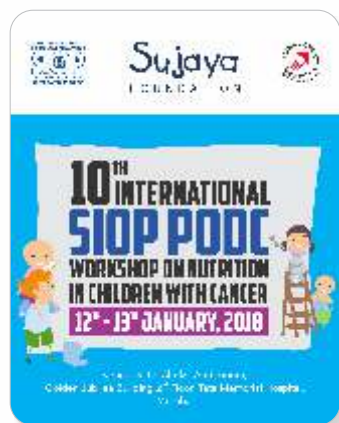
The 10th International SIOP-PODC Nutrition Workshop was held at Tata Memorial Hospital, Mumbai on 12th and 13th January 2018. This was the 4th such workshop to be held in India. There were close to 200 attendees from all India, of whom 44 were faculty, including three international speakers from Canada, USA and Bangladesh. Although most of the delegates were expectedly nutritionists , 30 doctors, 5 nurses and 10 allied health professionals also attended the workshop as delegates.

The workshop included key topics in paediatric oncology nutrition as well as other topics of contemporary relevance such as 'building international collaborations' and 'updates in research'. Based on feedback from previous workshops, the program focused on being interactive and encouraged discussion and debate.

All sessions were video recorded and have been uploaded to the website where they are available free of cost

[https://www.yearinreview.in/conference/tenth-international-siop-podc-day-1 ..](https://www.yearinreview.in/conference/tenth-international-siop-podc-day-1..)

Report : 10th International SIOP-PODC International Nutrition Workshop



FACULTY



DELEGATES

Message from CCI President



CCI: A NEW YEAR BEGINS

"It is a time to start where we are, use what we have and do what we can"



Dear CCI Colleagues,

As we start a new year we must look back upon the year that has just passed. For many of us, 2017 was filled with sadness and the loss of too many children who were gone too soon. More than 300,000 children around the world faced a childhood cancer diagnosis and too many of them had little hope for a cure. Some of these were our own children; some were children whom we served through our organizations. My hope is that time will bring healing and as former U.S. Vice

President Joe Biden said, "There will come a day when the thought of your son or daughter (or your husband or wife) brings a smile to your lips before it brings a tear to your eye."

2017 was also filled with the knowledge that as individuals, member organizations and together as CCI, we continued to serve children and adolescents with cancer and their families around the world. We raised awareness, increased access to care, staffed treatment centers, advocated to the highest levels of government regionally, nationally and internationally, created coalitions with other key stakeholders and provided support to hundreds of thousands of children fighting this disease, survivors and their families. Together, we grew to become the largest childhood cancer grassroots organization in the world with a global network of 188 member organizations in 96 countries all strongly committed to "Advancing Cure & Transforming Care." On behalf of the CCI Board of Trustees I want to thank each and every one of you for your commitment to our common vision that children and adolescents with cancer benefit from the best possible treatment, care and support wherever they live in the world.

As 2018 begins, we must also look forward to the year ahead. A new year brings the opportunities to dream and to take more steps towards the goals that will help to further this cause that is so dear to each of our lives. It is a time to start where we are, use what we have and do what we can.

- 📌 One opportunity to Build Awareness and Mobilize Support is through supporting CCI Signature Events including International Childhood Cancer Day (ICCD), which is held February 15th each year. (<http://www.internationalchildhoodcancerday.org>). We encourage all member organizations and childhood cancer stakeholders to participate on Feb. 15th 2018 to highlight the need for concerted local and global actions to address the growing challenges posed by childhood cancer.
- 📌 Another opportunity is to engage in collaborative initiatives with other CCI members and regional committees.
- 📌 We encourage you to take the opportunity to share expertise and learn from others through participation in CCI regional conferences as well as to plan ahead to attend the annual Congress which will take place in Kyoto, Japan Nov. 16-19th, 2018 (<http://siop-online.org/event/siop-2018/>)
- 📌 The CCI Board also encourages members to share your program successes via our newsletter and social media by sending summaries and pictures to: headoffice@cci.care

The CCI Board of Trustees is volunteers. Many do this in addition to leading CCI member organizations as well as their own careers. I couldn't be more proud to introduce the following 2018 Board of Trustees as approved at the AGA, October 14, 2017 in Washington DC.

NAME	Region	Role
Ruth Hoffman	United states of America	<i>President</i>
Carmen Auste	Philippines	<i>Immediate Past President, VP</i>
Luisa Basset	Spain	<i>Secretary</i>
João Bragança	Portugal	<i>Treasurer</i>
Marcela Zubieta	Chile	<i>Member</i>
Mary MacCowan	Australia	<i>Member</i>
Nicole Scobie	Switzerland	<i>Member</i>

On behalf of the Board of Trustees and myself, I wish all of you the best in 2018 as we work together to Advance Cure and Transform Care for children and adolescents with cancer.

Ruth Hoffman MPH,
President,
Childhood Cancer International



CCI Member: CHANCE, Lebanon **“Let Cancer Survivors Tell Us Their Stories”**

This summer, CHANCE (Children Against Cancer) Association empowered survivors by giving them the opportunity to tell their stories, realize their dreams and show their journey to cure during the annual fundraising event attended by over 700 people.

Pascale, cured from a sarcoma, made a very touching movie about her journey with a famous Lebanese movie producer. Simon cured from leukemia, always dreamed of being a football champ and played all sports with national champ Silvio and created an inspiration for more children to fight and be cured.

With the support of national televisions and social media, thousands of people heard these messages of hope. CHANCE Association, relying only on volunteering and donations has been financing the treatment of children in Lebanon in 5 hospitals for the past 15 years. It has helped over 700 children to be cured and covered over 10,000 hospital admissions. It is the first NGO in Lebanon to be a member of CCI since 2006.





CCI Member: MAHAK, Iran

“A Report on the 2nd International Congress on the Role of Supportive Bio-Psycho-Socio-Spiritual Services in Multidisciplinary Treatment of Childhood Cancer”

The 2nd International Congress on the Role of Supportive Bio-Psycho-Socio-Spiritual Services in Multidisciplinary Treatment of Childhood Cancer was held by MAHAK – the Society to Support Children Suffering from Cancer on November 22-23, 2017 at MAHAK with the presence of different national and international experts in fields of medical, social work and psychology including Prof. Eric Bouffet, Head of International Society of Pediatric Oncology and a representative from Ministry of Health and Medical Education.



This congress was organized in 5 specialized panels, workshops and different speeches of prof. Eric Bouffet, Head of International Society of Pediatric Oncology (SIOP); Charles Mbugua, International Federation of Social Workers' representative at United Nations; prof. Issarang Nuchprayoon from Chulalongkorn University; Prof. Claire Wakefield, Head of Behavioural Sciences Unit at Kids Cancer Centre and other experts.

As the opening part of "the 2nd International Congress on the Role of Supportive Bio-Psycho-Socio-Spiritual Services in Treatment of Childhood Cancer" Pariya Maavandi recited one of the versed stories of "Shahnameh", the longest ever epic written by a single poet

Medical Team Success; Only through Multidisciplinary Treatment



The congress' keynote speaker, Prof. Eric Bouffet, Head of International Society of Pediatric Oncology (SIOP) delivered a speech on 'the Importance of Multidisciplinary Treatment of Childhood Cancer' by mentioning his experiences and knowledge regarding the field of Multidisciplinary Treatment as the Head of SIOP and as the developer of a multidisciplinary pediatric Neuro-Oncology program in year 2000.

He emphasized that having multidisciplinary treatment is only possible when all doctors and caregivers collaborate to update the care and discuss the options of treatment and make the final decisions at the time of diagnosis or when the child has REDAPS in order to provide the best treatment for his/her.

In the end he compared multidisciplinary treatment to playing soccer in which without the team spirit you will never win. It is both good for the child and for doctors because of being time-efficient and providing the doctors with the sense of satisfaction in their career. He asserted that I do not see success for the medical staff without multidisciplinary treatment.

My Daughter's Cancer is not Sorrowful Anymore



The second day of the congress initiated by Saideh Ghods, the founder of MAHAK, expressing that transferring experiences on the first day of the congress has been very fruitful and has increased MAHAK's knowledge to provide better health and support services to cancer-stricken children and their families, shared her own experience in having a child with cancer and talked about the great change which has occurred in the situation of parents with cancer-stricken children today.

She talked about her personal experiences and challenges during her child's treatment and emphasized the importance of support services in coping with difficult situation and

ultimately the treatment of cancer. She also highlighted MAHAK's achievements during the past quarter-century through multidisciplinary treatment.

MAHAK's Approach towards support Services Provision Relying on Civil Society Capacity



The first panel entitled 'MAHAK's Approach towards Support Services Provision Relying on Civil Society Capacity' was held with the presence of Shahindokht Kharazmi, Writer and Social Analyst; Dr. Farhad Heydarian, Director of Dr. Sheikh Educational, Research and Therapeutic Center.

Dr. Azim Mehrvar, Pediatric Hematologist Oncologist and Head of MAHAK Hospital; Shirin Sediqnejad Manager of MAHAK's local Support Services Offices; Noaman Abdulrahman Ali, Project Manager of Kurdistan Save the Children (KSC) in Iraq; Dr. Mithra Ghalibafian, Head of MAHAK Hospital's Radiation Oncology Ward; Dr.

Mohammad Nasiri, Director of Health-Related Donors and Charities at Ministry of Health and Medical Education; and Ahmad Yazdanpanah, CEO of the Society to Support Children Suffering from Cancer in Khorasan.

During this panel, Noaman Abdulrahman Ali and Dr. Farhad Heydarian talked about their experiences of utilizing multidisciplinary treatment at their centers and other panel members from MAHAK shared their knowledge, experiences and challenges of utilizing multidisciplinary treatment at MAHAK hospital.

Medical Team Success; Only through Multidisciplinary Treatment



Prof. Issarang Nuchprayoon from Chulalongkorn University had a speech on 'Home Palliative Care for Childhood Cancer' and talked about his experiences, challenges and achievement of inaugurating home palliative care services in Thailand.

In his presentation, he studied many cases with various situations who have received palliative care accordingly. He also added that recently, he is running an online project of virtual physician in which he is able to be in contact with the patients and their families in order to be aware of the patient status and prescribe the necessary advice or medicines.

Congressional Statement



At the closing part of the congress, Ali Zadeh Mohammadi, the congress' Scientific Secretary recited the congressional statement:

"From the initiation of MAHAK – the Society to Support Children Suffering from Cancer, we have striven to provide cancer-stricken children and their families with the most efficient services through assessing their needs in line with our mission which is setting comprehensive care for this group.

In consideration of exchanging knowledge among national and international specialists and experts and creating a specialized overview on multidisciplinary treatment, MAHAK has held three organized specialized congresses on support services in 2010, 2013, and 2014.

The goal of organizing these congresses is to raise the level of knowledge and skills of the experts and volunteers who provide services to cancer-stricken children and their families. This was achieved through sharing of experiences with universities, scientific centers and other NGOs at national and international levels. Accordingly since 2014, MAHAK intended to hold this congress biennially with the participation of international specialists and speakers.

The 2nd International Congress on the Role of Supportive Bio-Psycho-Socio-Spiritual Services in Multidisciplinary Treatment of Childhood Cancer held on November 22-23, 2017, focused on the development of providing supportive services to cancer-stricken children and care givers (professional and family) in the process of multidisciplinary treatment approach in the stages of diagnosis, treatment, after treatment (follow-up), after remission, and grieving and post grieving. According to the presence of MAHAK's staff and volunteer social workers in all public and university hospitals throughout the country with pediatric oncology wards, it was decided that MAHAK will focus on the two fundamental issues of integration and comprehensiveness in its service provision throughout the country.

Rendering to the speakers and members of the scientific panels, it was decided that MAHAK continues to develop multidisciplinary treatment approach and define the common interests and goals of the medical, nursing, social and psychological groups in order to improve the quality of cancer treatment in Iran. This goal will be realized only with cooperation of all expert groups in the field of supportive and treatment services and undoubtedly, the success of this cooperation requires systemic thinking, integrated management, and decision making with respect for different specialized overviews.

It is decided to use this congress' findings and research and educational achievements in the form of multidisciplinary treatment approach to reduce the level of grief and to improve the quality of life in line with unified and integrated support of our children throughout the country.

Regarding the educational needs of MAHAK and other organizations' staff, it is stipulated that specialized workshops on different stages of treatment of cancer-stricken children and their families should be held during the year.

Establishment of parents' center was recommended for education, raising awareness and adaption assistance in treatment and particularly in parents' grief.

It was also decided that this biennial congress will be continued focusing on multidisciplinary treatment of childhood cancer with the presence of national and international speakers and researchers. It was suggested that a systematic study to be carried out on the needs assessment of different stages of cancer from diagnosis to follow-up or grieving by MAHAK."



CCI Member: Cancer Patients Aid Association, India “Rose Day 2017”

Rose Day in India, Cancer Patients Aid Association's call for the public to connect with cancer patients in a non-medical way was launched on September 22, 1994. It was created as a way for laypeople to express compassion and goodwill towards patients undergoing treatment at hospitals and treatment centres all over India. Twenty three years running, Rose Day has evolved, touched, moved, inspired adult and childhood cancer patients for just a while, lifting them out of an abyss to rekindle hope in their lives. It has also raised funds towards CPAA's long-term goal of 'Total Management of Cancer'.

The concept of Rose Day came from the conviction, “Everyday people do care. They do have heart. Let's not underestimate the goodness and goodwill of the common man like you and me. At a price that's affordable across segments, let's draw people into a conversation about cancer in a non-intimidating way. Gifting a Rose costs just Rs.10/- with a message of love had the power to make patients smile as well as address bigger issues such as misconceptions about the disease (those were rampant 20 years ago); collectively focus on cancer as a nation and do our little bit to make the difference. Rose Day emerged as that opportunity to channelize compassion into a sustainable campaign against cancer. Nurtured and grown by CPAA's band of committed volunteers and workers, 22nd September, 2017 is today observed as National Cancer Rose Day in India.

We celebrated Rose Day this year, dedicating ourselves, as usual, to bringing smiles to adult and childhood cancer patients. From 14th September to 14th October, 2017, efforts were focused on bringing magical moments of relief to cancer patients through warm, heartfelt gestures—gifts, song, dance, music and fun. The highlight of the project is a mass distribution of goodie bags laden with utilities/toiletries/toys and goodwill messages to over 1000 patients at treatment centres across Mumbai. Appropriate entertainment was organized to create moments of fun for the patients in various hospitals and dharamshalas.

Kids were given bags stuffed with toys, colouring books, crayons, story books and other goodies. Dance, song programmes brought them to their feet.





CCI Member : Cankids...Kidscan, India
“Car Rally Change for Childhood Cancer and
Second Paediatric Haematology Oncology Support Services Conference”

GO GOLD PUNJAB CHILDHOOD CANCER AWARENESS CAR RALLY CHANGE FOR CHILDHOOD CANCER

IN PUNJAB was held from 23rd to 28th September 2017. The aims of the event were to raise awareness, engage stakeholders, raise funds for children with cancer, and advocate with Central and State Governments for childhood cancer. The rally covered over 1300 kms through 15 districts of Punjab over a period of 5 days from Delhi to Chandigarh, Bhatinda, Amritsar, Ludhiana and Rail Majra Ropar. The rally was organized by CanKids...Kidscan partnering with Chandigarh Motor Sports Association, as a licenced FMSCI Time Speed Distance (TSD) Rally. There were 19 cars in which 59 participants including 14 childhood cancer survivors have generated awareness through 17 awareness programs, community mobilization and social dinner. CanKids reached to more than 1 crore people through media coverage. Also, the first state Memorandum of Understanding (MOU) was signed between CanKids and the Government of Punjab, India on 14th September 2017.





CCI Member: Aroh-Giving Hope, India

“Rally with Harley Davidson in Childhood Cancer Awareness Month”

Aroh conducted various awareness programmes in the month of September in two different states, Kerala and Tamil Nadu in India. The event that got us the most media coverage was the one in Kochi on September 24th.

Aroh tied up with the Harley Davidson Customer Group to do an awareness rally for us. The rally was flagged off by a famous Film star called Rima along with 2 Pediatric Oncologists from the city, Dr.Hari and Dr.Raghu. 30 riders, both men and women, participated in the rally and every print media covered the event. Ms.Rima posted about the event in her Facebook page which again was picked up by the media!

It was a nice surprise when one of the riders disclosed that his son is undergoing treatment for cancer in another city. It brought the group together for this cause.





CCI Member: Yayasan Anyo Indonesia “1.000 ophthalmoscope movement”

As retinoblastoma is the second most common type of cancer after leukemia in Indonesia, and is the only type of cancer in children that can be detected early, therefore YAI (Yayasan Anyo Indonesia-The Indonesian Anyo Foundation) initiated the '1.000 ophthalmoscope movement' where 1,000 units given to YAI from individual donors, groups and companies to be distributed complimentary to 1.000 primary health care in 34 provinces in Indonesia (there are about 10,000 primary health care in Indonesia).

By this effort, hopefully more children with retinoblastoma found at earliest stage, to save not only their life, but also their eyes and vision.

In November 2017, collaboration with YKI (The Indonesian Cancer Foundation) educated 25 primary health care's doctors in Merauke, Papua, Indonesia about childhood cancer including retinoblastoma. The guidebook on early detection of childhood cancer facilitated by YAI and 25 ophthalmoscope given to 25 primary health care there.



early detection of retinoblastoma by 'see red' or ophthalmoscope in Merauke, Papua, Indonesia

1. Annual Meeting of American Society of Paediatric Haematology-Oncology (ASPHO) 2018

When : May 2nd -5th , 2018

Where: Pittsburg (PA), USA

<http://aspho.org/meetings/conference/2018-conference/2018-conference>

2. Advances in Neuroblastoma research (ANR) 2018

When: San Francisco, California

Where: May 9th -12th , 2018.

<http://anr2018.org/>

3. Annual meeting of Multinational Association of Supportive Care in Cancer (MASCC) 2018

When : June 28th - 30th , 2018

Where : Vienna, Austria

<http://www.mascc.org/2018-annual-meeting-invitation>

4.18th International Symposium on Pediatric Neuro-Oncology (ISPNO) 2018

When: June 29th-July 3rd, 2018

Where: Denver, Colorado, USA

<http://ispno2018.com/>

5. 7th International Symposium on Pediatric Solid Tumors

When : September 28th -29th , 2018

Where: Tübingen, Germany

<http://www.sarcoma-tuebingen2018.com/>

6. 6th International Symposium on Childhood,Adolescent and Young-Adult Non-Hodgkin Lymphoma

When: September 26th -29th , 2018

Where: Rotterdam, the Netherlands

<http://www.cayanh12018.com/>

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