

ICCCPO Meeting ASIA 2012

Jogyakarta, 21-24 April 2012

Sekretariat : Jl. Percetakan Negara IX/10A, Jakarta Pusat 10570
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Report on ICCCP MEETING ASIA 2012
Yogyakarta-Indonesia 21- 24 April 2012

The ICCCP-ASIA 2012 meeting with the theme: GIVE HOPE to CHILDREN WITH CANCER was concurrently held with the pilot project: OUR VOICE, STRENGTH & WELLBEING conducted by the Survivor Program Committee, and organised by the Indonesian Care for Cancer Kids Foundation (Yayasan Kasih Anak Kanker Indonesia) and Indonesian Childhood Cancer Foundation (Yayasan Oncology Anak Indonesia) both of which are members of ICCCP.

The meeting was attended by 37 participants including survivors from 18 organisations/institutions from various countries such as Bangladesh, Vietnam, Nepal, Singapore, Malaysia, Japan, Korea, the Philippines, Iran and Hongkong; all of those are members of ICCCP.

Among the participants from Indonesia were several parents of children with cancer organisations, survivors, institutions, hospitals for children with cancer and interest groups from various cities such as Semarang, Surabaya, Medan, Padang, Palembang, Makassar, Manado, Yogyakarta, Jakarta which totalled to approximately 160 persons.

The meeting was divided into two groups:

- A. Parents and interest groups (ICCCPO meeting at the LPP Garden Hotel, Yogyakarta)
- B. Survivors meeting held in TEMBli Cultural House, Jalan Parangtritis, Yogyakarta.

The Plenary session of the SIOPI (International Society of Pediatric Oncology)-Asia meeting on the 22nd of April 2012 (at the Sheraton Mustika Hotel), which was planned to be officially opened by the Indonesian Minister of Health Mrs. Dr. Endang Rahayu Sedyaningsih, but due to her illness it was delegated to the Vice Minister, Dr. Ali Guffron from the Indonesian Ministry of Health. Later, the Minister of Health lost her battle against lung cancer and passed away on the 2nd of May.

Keynote speakers were Dr Badriul Hegar, Chairman of the Indonesian Paediatric Society, Mr. Akira Nakagawara, SIOPI Continental President, Dr. Gabriele Calaminus, SIOPI President, and Mr. Benson Pau representing ICCCP and World Child Cancer.

During the opening ceremony of the ICCCP-ASIA 2012 Meeting, which was also held at the Sheraton Mustika Hotel, it was planned that the Minister for Women Empowerment & Child Protection would attend the meeting. But due to various reasons she was unable to attend and was represented by the Deputy Minister Dr. Wahyu Hartomo MSc. Also Dr. Untung Suseno, delegate of the Indonesian Minister of Health, spoke at this occasion.

Organized by:



Yayasan Kasih Anak Kanker Indonesia
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Apart from information sharing sessions amongst the ICCCP members from various countries, this meeting was also used as a forum for different stakeholders in Indonesia to get to know each other, to socialize and to give the Directorate General for Non-Communicable Diseases the opportunity to inform the public about the Guidelines for Introduction of Childhood Cancer. This was the first time that this information was given publically and it was done by Dr Endang Windiastuti, Head of Haematology/Oncology Division of the Dr.-Cipto-Mangunkusumo-Hospital.

The working committee of the ICCCP-ASIA Meeting 2012 which was chaired by Prof. Dr. Iskandar Wahidiat included for the first time a Survivors Meeting, which was set up in collaboration with the psychologists from the Sardjito Hospital, Faculty of Psychology University of Gajah Mada (with all costs funded by the working committee).

The survivors meeting with the theme: OUR VOICE, STRENGTH & WELLBEING, is a pilot project put together by Mrs. Erlin Erlina, survivor from Yogyakarta, who is married and has 2 children, and Dr. Gamayanti, Medical Psychologist, and her team. Indeed it was a collaborative work between clinical psychologists and general practitioners, a full and very interesting program. It was unfortunate that Mrs. Erlin Erlina was not able to be involved further as she had to go to Australia before the meeting.

Young cancer survivors participated in the whole program and were fully supported and facilitated throughout the process. Their participation was based on mutual respect and they were given the right to voice their views and opinions and to define their needs and hopes, as these are a valuable contribution to organize the psychosocial support affecting them. The Youth Cancer Voice Program is based on a participatory method grounded by the young adult partnership. The activities are guided by the young cancer survivors' voice to identify their strengths and potentials and promote their wellbeing. At the end of the program, their voice was presented in the ICCCP meeting and surprisingly at the 7th SIOPIA ASIA Congress too. During their presentation they presented their own declaration which expresses their wishes and feelings (the declaration is attached).

The 'Meet & Greet' evening organized by the committee promoted the aspects of socialising and relaxation. A singer accompanied by a single keyboard player entertained the group. As part of a tradition of ICCCP, each organisation brought food/traditional snacks from their own countries; and the local participants brought their food specific to their region. Also, it was planned that all participants would wear their traditional outfits. The committee provided an Indonesian buffet dinner.

It was a happy evening, opened by the Head of the Indonesian Childhood Cancer Foundation, Mrs Rahmi Tahir, and it was followed by a fashion show from each country and region (attached find the

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photos of the evening). Special guests of the evening were Mr Benson Pau and his wife Amy, the SIOPIA Chairperson, Dr. Gabriele Calaminus, as well as the SIOPIA-Asia Continental president, Mr. Akira Nakagawara, the SIOPIA-Africa President, Prof Mariana Kruger, and Mr JJ de Vino.

The opening of the survivors' meeting which was held in the TEMBI Cultural House was a special attraction on its own: TEMBI is located \pm 45 minutes from LPP GARDEN. It is a beautiful accommodation complex with gives a peaceful atmosphere in the simplicity of nature. The committee provided a bus for the participants. Parents and nurses who arrived earlier at the LPP Garden Hotel attended the opening evening of the survivors meeting. The evening started with the opening remarks by Mrs Gamayanti, the chairperson of the survivor program committee, followed by music and dance entertainment and a unique traditional buffet dinner (photos attached).

On April 23rd, all ICCCP participants as well as the survivors had the opportunity to watch together with SIOPIA participants the Sendratari Ramayana. The evening was started by dinner and closed by a wrap-up-discussion attended by all participants including the survivors.

BENEFITS OF ATTENDING THE ICCCP MEETING ASIA 2012:

1. ICCCP is an international social organisation; the presence of various ICCCP members from developed as well as developing countries provides direct access to information about the development of cancer management in each country.
2. The momentum of this meeting with the theme "Give HOPE to CHILDREN with CANCER" could well be utilised to invite affected parents as well as related individuals/organisation/institution from many regions in Indonesia to get to know each other and to join efforts. It is hoped that this may speed up the improvement of childhood cancer treatment.
3. WRAP-UP DISCUSSION amongst ICCCP participants which included parents, nurses, doctors and survivors.
4. The young survivors meeting from Indonesia and Asia which was managed by the committee together with the psychologist Mrs. Gamayanti and the Sardjito Hospital psychology team as a pilot project "OUR VOICE, STRENGTH & WELLBEING" is a new breakthrough and it produced the survivors declaration, which has been presented to the ICCCP Meeting-ASIA 2012 and the 7th SIOPIA ASIA Congress 2012 participants.

Jakarta, May 2012

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