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Asian Pediatric Hematology and Oncology Group (APHOG) and SIOP Asia: Two wheels of a cart

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ABSTRACT

Around 60–70% of the world population are residing in Asia and each year approximately 200,000–250,000 children and young adolescents aged less than 20 years are expected to develop cancer. The Asian continental branch of the International Society of Pediatric Oncology (SIOP Asia) was founded in 1995 and its first meeting was held in Singapore in 2000. Since the SIOP Asia is an academic society under the umbrella of SIOP, foundation of its action team named as Asian Pediatric Hematology and Oncology Group (APHOG) was proposed and agreed to be built by the representatives from many Asian countries in 2012 at the time of the 7th SIOP Asia congress in Yogyakarta. APHOG is an Asian children's cancer clinical study group which works as one of the two wheels of a cart with SIOP Asia. One of its new missions is to support the WHO Global Initiative for Childhood Cancer which was declared in 2018. The aim is to increase the cure rate of children with cancer up to more than 60% by 2030. The fundraising system for APHOG is now being established.

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1. Introduction

Asia is composed of about 50 countries whose levels of the gross domestic product (GDP) per person are diverse and ranging from low- to high-income countries. In high-income countries (HICs) in Asia like Japan, South Korea, Singapore, Hong Kong, UAE and Taiwan, the cure rate of pediatric cancers is nearly 80%, while that in low- and lower-middle income countries (LMICs) in Asia is still 10–30%. [1]. The causes of such poor outcome in LMICs include failure in establishing diagnose, misdiagnosis, abandonment of therapy, treatment-related death, and high relapse rate. In 2018, World Health Organization (WHO) declared that this kind of inequality should not be present, and that the cure rate of childhood cancer on earth should be increased up to more than 60% by 2030, which is named as “WHO Global Initiative for Childhood Cancer” (Fig. 1). [1].

The initial founders of International Society of Pediatric

Oncology (SIOP) decided to form Pediatric Oncology Club in 1967 and the first SIOP meeting was held in 1969 in Madrid, Spain. There were 28 founding members and they forest up the constitution. [2]. SIOP has six continental branches, Africa, Asia, Europe, North America, Oceania and South America, among which Asia is the largest and accounts for more than 60% of world population.

The first SIOP meeting held in Asia was the 30th Congress of SIOP (1998) at Yokohama, Japan. It was followed by the 39th SIOP (2007) in Mumbai, India, the 45th SIOP (2013) in Hong Kong, China, and the 50th SIOP (2018) in Kyoto, Japan. The number of participants was only about 1000 from 50 countries at the SIOP (1998) in Yokohama, and it has largely increased to more than 2500 from 90 countries at the SIOP 2018 in Kyoto. Thus, SIOP has grown significantly, suggesting that the children with cancer and their parents really need the support and help from the SIOP. The vision of “no child should die of cancer” and that “cure can be achieved with no or minimal late effects” is a common goal for all people including Asians.

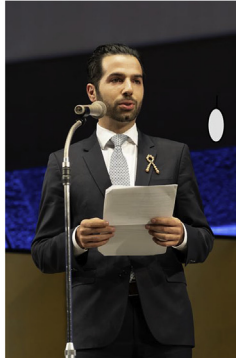
However, since SIOP or SIOP Asia is an academic society, it needs an execution arm to conduct clinical studies and implement changes in standard of care in order to achieve the goal of WHO Global Initiative for Childhood Cancer in Asia. Therefore, to activate APHOG as one of the two wheels of a cart with SIOP Asia is required

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“WHO Global Initiative for Childhood Cancer”
The goal is to achieve at least 60% survival for all children with cancer by 2030.



Dr. Andre Ilbawi, WHO, at the SIOPEL 2018 in Kyoto



SIOPEL Advocacy Landmark Event I 68th World Health Assembly, 18 May 2015
 (from left to right: Fritz Pleitgen, Gabriele Calaminus, Giorgio Perilongo and Ralf Herold)
 (Courtesy of SIOPEL homepage)

Fig. 1. The WHO Global Initiative for Childhood Cancer. WHO and SIOPEL will work together for all children with cancer in the world.

(Fig. 2). Similar scenario has been observed in SIOPEL Europe where various study groups are derived from the original SIOPEL network such as SIOPEL (neuroblastoma), SIOPEL (liver cancers), etc.

2. History of SIOPEL Asia

Recently it was reported that ~429,000 children and young adolescents aged 0–19 years are expected to develop cancer

around the world annually. [3]. We estimate that about 260,000 children and young adolescents will be from Asia.

SIOPEL Asia was founded by the SIOPEL Board and Dr. Yoshiaki Tsuchida who was elected as the first continental president of Asia in 1995. He hosted the main SIOPEL congress in 1998 at Yokohama. The following continental presidents of Asia were Dr. Tadashi Sawada (Japan, 1998–2001), Dr. Bharat Agarwal (India, 2001–2004), Dr. Yaoping Wang (China, 2004–2007), Dr. Purna

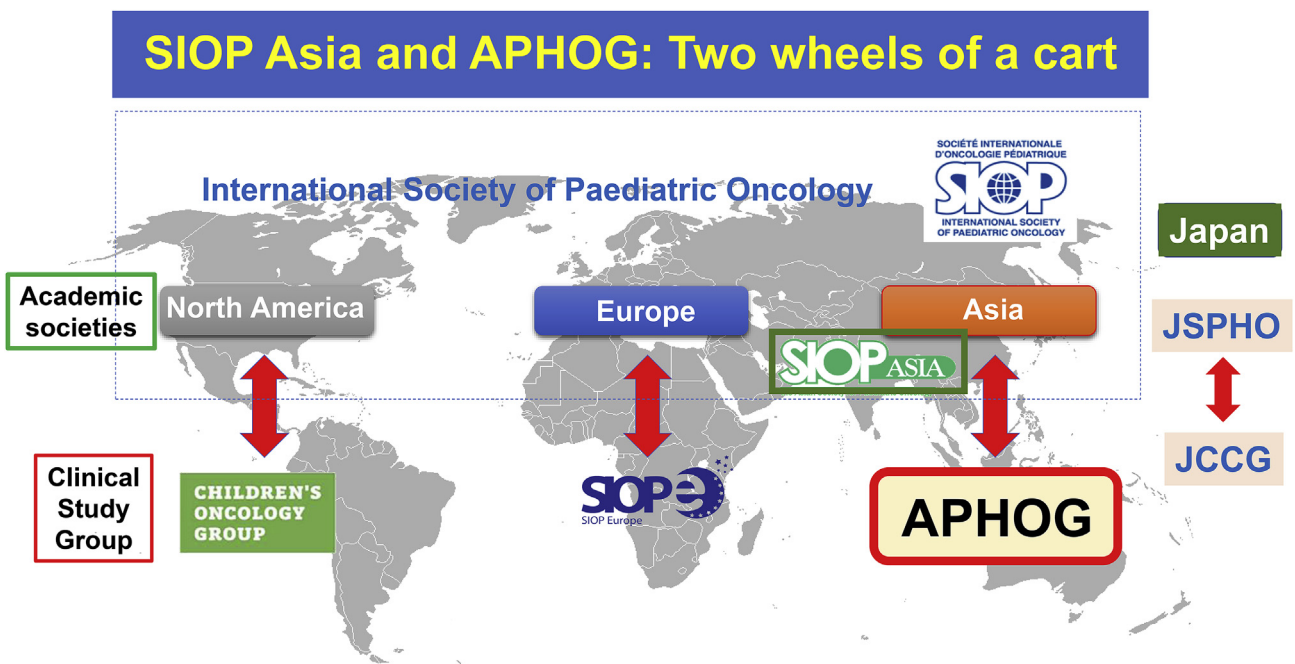


Fig. 2. SIOPEL Asia and APHOG are two wheels of a cart. SIOPEL Asia is an academic society whose tasks are mainly education, advocacy and exchange of information. On the other hand, APHOG works as an action team of SIOPEL Asia with tight collaboration to increase the cure rate of childhood cancer in Asia and to further encourage the survivorship of the patients. The similar style is also present in North America, Europe and Japan.

1st APHOG Meeting



April 24th, 2012
Yogyakarta, Indonesia

Fig. 3. A picture of the first APHOG meeting held in Yogyakarta, Indonesia, at the meeting of SIOP Asia 2012.

Kurkure (India, 2007–2010), Dr. Akira Nakagawara (Japan, 2010–2015), Dr. Chi-Kong Li (Hong Kong SAR, China, 2015–2018) and Dr. Rashmi Dalvi (India, 2018–present).

The first SIOP Asia Congress was held in Singapore in 2000, and the followings were held biannually at New Delhi, India (2nd, 2002), Dhaka, Bangladesh (3rd, 2004), Shanghai, China (4th, 2006), Muscat, Oman (5th, 2008), Kish Island, Iran (6th, 2010), Yogyakarta, Indonesia (7th, 2012) and Seoul, Korea (8th, 2014). After then, the SIOP Asia Congresses have been changed to annually with exception for those year when main SIOP meeting is held in Asia. Therefore, the venues of SIOP Asia were followed by Amman, Jordan (9th, 2015), Moscow, Russia (10th, 2016), Bangkok, Thailand (11th, 2017), and Abu Dhabi, UAE (12th, 2019). The next SIOP Asia

Congress is scheduled to be held in Mumbai, India, in March, 2020.

Thus, the venue of SIOP Asia Congress rotates among the Asian countries and the contents of the congress are catering for domestic needs. The participants are mostly local professionals from the host country and composed of pediatric oncologists, pathologists, radiation oncologists, pediatric surgeons, nurses, patients or survivors, parents, engineers, students and volunteers. Most of these participants cannot afford to attend the main SIOP meeting abroad because of the financial burdens related to the transportation, oversea accommodation and registration fee. Most of them are very eager to learn about the state of the art methods in diagnosis and treatment. In addition that it increases the awareness of the role of SIOP in a global sense, it also creates a vast human network within

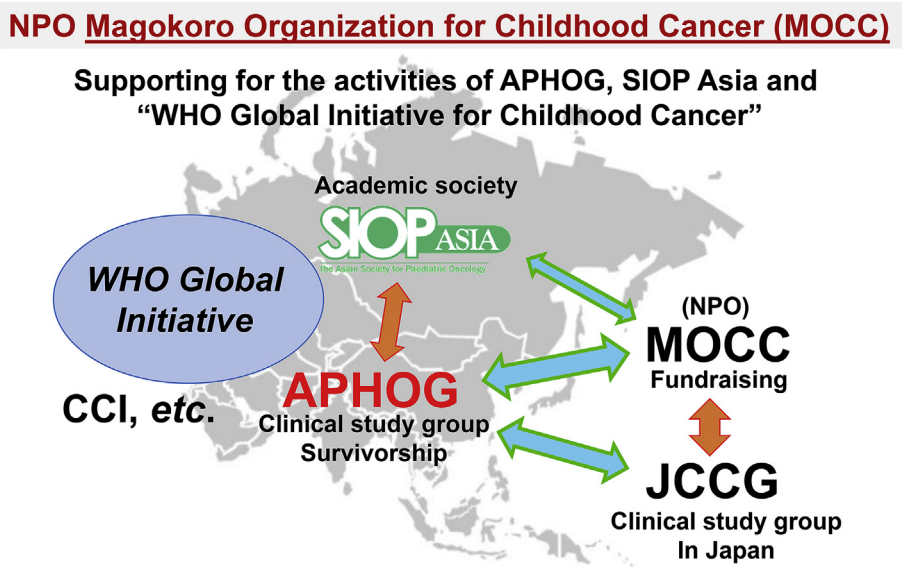


Fig. 4. The non-profit organization Magokoro Organization for Childhood Cancer (MOCC) works with Japan Children’s Cancer Group (JCCG) to mainly support for the activities of APHOG by fundraising.

Asia and beyond. As a consequence, we witness a steady increase in the number of the SIOP membership from Asian countries.

However, since the SIOP Asia is an academic society under the umbrella of SIOP and mainly concentrates on education, advocacy, training and exchange of information with very few budget, we needed another team, APHOG, to conduct actual clinical studies.

3. Asian Pediatric Hematology and Oncology Group (APHOG)

3.1. Concept

APHOG is a non-political, non-commercial, non-profit making organization with the aim to connect and help all pediatric hematology and oncology professionals, patients, parents and volunteers in Asian region to improve the diagnosis, treatment and care of childhood cancers. It is actually the integrated pediatric cancer clinical study group of Asia. APHOG is an clinical study arm of SIOP Asia which complements the works of SIOP and SIOP Asia. They all share the common goal of “no child should die of cancer and that cure can be achieved with no or minimal late effects”.

3.2. Aim and tasks

1. To help exchanging updated information on pediatric hematology and oncology in Asian countries.
2. To help organizing Asian international collaborative study group(s).
3. To promote the establishment of a database system for pediatric cancers in Asian countries.
4. To support long term follow up and means to improve the quality of life for childhood cancer survivors in Asia.
5. To facilitate the development of “advanced personalized therapies” for all children with cancer in Asia.
6. To enhance the pediatric hematology and oncology researches in Asia.
7. To establish pediatric cancers tissue bank (biobank) in all Asian countries which can facilitate translational research of pediatric cancers in Asia.
8. To help solving the ethical issues in the field of pediatric hematology and oncology in Asia.
9. To protect children from having unnecessary therapy such as excessive radiation exposure in Asia.
10. To collaborate with other international pediatric oncology study groups via networking.
11. To help developing practical and effective therapies based on the availability of different software and hardware in various socio-economic strata. (No. 11 was proposed by Dr. Giulio J. D’Angio.)

3.3. The short history

APHOG was initially proposed to increase the cure rate and the quality of life of children with cancer in Asia in close collaboration with SIOP Asia in 2012 (Fig. 3). The previous meetings are listed as follows.

2012 April 1st APHOG meeting in Yogyakarta, Indonesia (at SIOP Asia 2012).

2012 June 2nd APHOG meeting in Toronto, Canada (at ANR 2012 meeting).

2012 October 3rd APHOG meeting in London, UK (at SIOP 2012).

2013 August 4th APHOG meeting in Tokyo, Japan.

2013 September 5th APHOG meeting in Hong Kong (at SIOP 2013).

2014–2018 Some small APHOG meetings by leaders.

2019 April 6th APHOG meeting in Abu Dhabi, UAE (at SIOP Asia 2019).

2019 October 7th APHOG meeting in Lyon, France (at SIOP 2019).

Since Asia is so huge, it was once proposed to divide it into two or three regions (2013, Tokyo). However, none of the representatives gathered agreed to do so. One of the biggest problems to activate APHOG has been a lack of funding support to conduct the action plans of the organization for a long time. Therefore, the Mogokoro Organization for Childhood Cancer (MOCC), a non-profit organization, has recently been founded in Japan to financially support the APHOG as well as other Asian groups with the same aim (Fig. 4). “Magokoro” stands for sincerity or a true heart.

3.4. Structure of APHOG

Although the structure of APHOG is still under formation, the followings are planned to be set up. APHOG is composed of Executive Council, Administrative Board, Scientific Council, Data Center, Biobank, and Members Operation Center. In Scientific Council, there are Fundamental Committees (Developmental Therapeutics, Epidemiology/Registry, Survivorship/Supportive Care, and Genetics/Predisposition), Disease Committees (Hematological Diseases and Solid Tumors), and Discipline Committees (Statistics, Surgery, Radiation Oncology, Hematology/Oncology, Pathology, Cytogenetics, Neurology, Nursing, Diagnostic Imaging, Laboratory Science, Pharmacy and Stem Cell Transplant). However, since it may take time to establish the whole structure, the first core committees will be formed and then other committees can follow. It is very important that all Asian countries and clinical research groups should be included at least at the final stage. Discussions are done mostly on the web conference or by using various information and communication network.

There are already about 10 proposed clinical projects which are under discussion at this moment (APHOG meeting at the SIOP 2019 Lyon).

3.5. Fundraising

A lack of funds has largely delayed the actual function of APHOG. Therefore, the constitution of NPO-MOCC, which originally aimed to construct an information and communication technology (ICT)-based long term follow-up system for children with cancer in Japan, was changed to mainly support for the WHO Global Initiative for Asian childhood cancer. We really need not only MOCC but also some other charity organizations to support fundraising for the APHOG function in the near future. MOCC, which has the office based in Japan, is the first one of such fundraising system, but the other similar groups in some Asian countries or cities are also needed. Cloud funding and other types of donations are also important for supporting the APHOG.

3.6. APHOG and the WHO Global Initiative for childhood cancer

One of the final goals of APHOG is to increase the cure rate of childhood cancer in Asia in tight collaboration with SIOP Asia, that completely matches the goal of WHO Global Initiative for Childhood Cancer. Therefore, APHOG should closely collaborate with both SIOP Asia and WHO also by working with the children’s cancer clinical study groups of individual Asian countries (Fig. 4). For example, APHOG should closely collaborate with Japan Children’s Cancer Group (JCCG) which is an action team of the Japanese Society of Pediatric Hematology/Oncology (JSPHO) to achieve the goal of WHO Global Initiative. Of course, the helps are mandatory from other major adult cancer centers such as National Cancer Center Japan as well as the Japanese government.

4. Discussion

Asia is a huge continent composed of about 50 countries with a diverse history, tradition, language, religion, political system, economical level and cultures. However, the value of life for each child, with or without cancer, should be the same for all countries in Asia.

SIOP was founded about 50 years ago with the goal of “no child should die of cancer”. The role of SIOP has been pivotal in building the standard of care for childhood cancer and it may even be more important in the future. However, since she is an academic society mainly concentrating on teaching and training via information exchange, an executive arm for conducting clinical study has to be formed. APHOG that we propose is such action team of SIOP Asia. APHOG should embrace the pediatric hematology and oncology research groups, and the membership should also extend to survivors, parents, nurses and volunteers of all Asian countries in collaboration with SIOP Asia. Thus, APHOG serves as one of the two wheels of a cart with SIOP Asia.

In Japan, both the Japanese Society of Pediatric Hematology and the Japanese Society of Pediatric Oncology were unified in 2011 to be the Japanese Society of Pediatric Hematology/Oncology (JSPHO) which is an academic society. On the other hand, various individual clinical study groups of pediatric solid tumor and leukemia/lymphoma were integrated into one to form the united Japan Children's Cancer Group (JCCG) in 2014. This is a clinical study group closely collaborating with JSPHO as its action team. [4]. Now, a lot of funds are coming mainly from the Japanese government to activate the JCCG function, that has never happened before. Therefore, JSPHO and JCCG are also the two wheels of a cart in Japan.

APHOG can collaborate with national or regional clinical study or research group(s) in each Asian country because many countries in Asia already established such kind of clinical study group for pediatric hematology and/or oncology in their own country. For example, like JCCG and InPOG in Japan and India, respectively. Since the representatives of those groups become the members of some APHOG committees, they can share with the group according to particular protocol in consensus.

The vision and works of APHOG are global and collegial. APHOG can collaborate with other continental study groups such as COG in North America and SIOPEN/SIOPEL in Europe, etc.

In 2018, WHO declared the Global Initiative for Childhood

Cancer and started to work toward the goal together with SIOP, Union for International Cancer Control (UICC) and Childhood Cancer International (CCI). WHO has already started to target the countries whose cure rate of childhood cancer should be increased up to more than 60% by 2030 (reported at SIOP 2019 Lyon). That includes Myanmar, Ghana and Peru. In a sense, the WHO's way is vertical and pin-point target strategy, while the way of APHOG/SIOP Asia appears to be horizontal and covers most countries in Asia. Thus, there is no duplication of the role and this can be the best way to solve the problems in Asia.

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