

SIOP-ASIA NEWS

Vol.4 No. 1 "Childhood Cancer is Curable", Let build on our past Jan 2005

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From the Editor:

Welcome the new Executive Board of Asian SIOP

With the establishment of Asian Chapter of SIOP, we have been under the leadership of Dr. Tsushida, Dr. Sawada and Dr. Agarwal. The organisation is now more structured; we have our constitution, newsletter, biennial SIOP-Asia conferences. This year, we also have our president elected through ballot by all the members in Asia. Professor Yao-ping Wang from Shanghai, China is the newly elected president. Congratulation!! The past Executive Board had completed the 3 years term and election of the new Board members at the General Body Meeting was held on September 17, 2004 at Oslo, Norway. Thirty-five members attended the meeting during the lunch time and that was held in a Cinema! The newly elected Executive Board members are:

President: Dr. Yao-ping Wang, Shanghai, China Secretary: Dr. Jing-yan Tang, Shanghai, China

Immediate Past President: Dr. Bharat Agarwal, Mumbai, India (Ex-Officio)

Executive Board Member: Dr. Fumio Bessho, Japan

Dr. Zakia Al Lamki. Oman

Dr. Anupam Sachdeva, Dehli, India Dr. Seunghoon Choi, Seoul, Korea Dr. Sutaryo, Yogyakarta, Indonesia Dr. Cheng-ren Shi, Shanghai, China. Dr. Rashmi Dalvi, Mumbai, India (Co-opted)

Dr. AA.H.Pour Feizi, Tabriz, Iran (Co-opted)

Editor of Newsletter: Dr. Chi-kong Li, Hong Kong, China

The new Executive Board will serve for 3 years from 2004. The minutes of the General Body meeting is attached as Appendix 1.

During the Annual Body Meeting at Oslo, Dr. Agarwal on the left, Dr. Wang in central and Dr. Dalvi on the right.



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MESSAGE FROM THE NEW PRESIDENT OF ASIAN SIOP

Prof. Yao-ping Wong
Newly elected President, SIOP-Asia

Dear Members of SIOP-Asia

It's a great honor for me to be elected as the President of SIOP Asia and actually it's also a big challenge. Since, Asia is a large continental area covering one third of the world population with majority of countries belonging to the developing countries. On the whole, the development of economy and modern technology is also not as good as that of the developed countries, but the incidence of Childhood Cancer is approximately similar to that of developed countries. Majority of the children with cancer can't get appropriate treatment, even give up when their parents know the diagnosis of cancer. How to help these children is a very difficult task facing as it needs us to make great contribution and good collaboration, but even in our continent, the pace of development in economy and modern technology is also not uniform. Some countries like Japan and Singapore are much faster and better. So, they can play a very important role in helping and promoting the development of other Asia countries. Let's unite together and make good collaboration to make great dedication for helping the children with cancer in Asia. I'll greatly appreciate your help and dedication and be looking forward to well coming you in Shanghai, China SIOP Asia 2006 on April 8, 2006 and also wish to use the news letter to communicate with all the SIOP-Asia members. Welcome you to make suggestion and send the papers on your experience.

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SIOP ASIA: OFFICIAL SEAT MOVES TO CHINA!

DR. BHARAT R. AGARWAL

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SIOP Asia has now existed for about 12 years: Japan managed the official functions for the initial 9 years. Later the office moved to India. And now the official seat and the focus is on China! The SIOP Asia membership has elected Prof. Wang Yao Ping as the new President. Dr. Jing Yan Tang (China) is nominated as the Secretary of SIOP Asia and Dr Chi Kong Li (Hong Kong) as the Editor for the SIOP Asia newsletter. The new executive board of SIOP Asia consists of Dr Fumio Bessho (Japan), Dr Zakia Lamki (Oman), Dr Anupam Sachdev (India), Dr Choi (Korea), Dr Sutariyo(Indonesia) & Dr.AA.H.Pour Feizi (Iran), Dr. Cheng-ren Shi (China). I welcome the new team of office bearers and I am quite sure that we can look forward to more activities and developments in the coming 3 years under the leadership of Dr. Wang.

I thought it appropriate to reflect on the achievements of the past 3 years.

- Membership base has increased and widened (we have > 200 members)
- Regular biennial conferences are being held by rotation in various countries of Asia.
- 10% of conference savings support SIOP Asia office and activities.
- Newsletter is published biannually (Dr. Li has informed me that he has already obtained sponsorship for this publication for the next 3 years!)
- Promotion of networking among individuals, groups and institutions.
- Dhaka declaration on "Childhood cancer is curable"
- SAARC initiative launched to promote education and collaborative clinical trials in the region.
- Information on the status of pediatric oncology servives & programmes in various countries has been disseminated

- Regular GBM,s (5 times in three years) organized for exchange of views / ideas amongst members.
- Parents programmes and organizations encouraged. Both the past 2 years SIOP Asia meetings had their active participation.
- Young investigator awards instituted for best free paper and poster papers at the SIOP Asia conferences.
- Future 2 meeting in 2006/08 at Shanghai, China and Muscat, Oman already announced.
- Website of SIOP Asia thoroughly updated at www.siop.nl/siopasia

All this would not have been possible without the active co-operation of the SIOP Asia executive board particularly, the assistance and contribution of the outgoing secretary and editor: Dr. Rashmi Dalvi and Dr. M.R.Lokeshwar. I also acknowledge the efforts of the organizing committees of 2nd and 3rd SIOP Asia conferences led by Dr. L.S.Arya and Dr. M.A.Mannan respectively. The main SIOP Board including the President Dr. Allan Craft have been extremely supportive of all SIOP Asia initiatives. The enthusiasm of the members and parents has been highly infectious. I am quite pleased with what we could achieve as a team for SIOP Asia in past 3 years. It was indeed a pleasure to have had the opportunity to work as the President of SIOP Asia. I wish the incoming team all the best. I look forward to meet all SIOP Asia members (& other SIOP members, who are welcome too!) at Shanghai, China in 2006. Please mark your calendars and do decide to come to Shanghai with your colleagues, post graduate students and spouses!

Introduction of Regional Development in Care of Childhood Cancer

Prof. Yao-ping Wang, Prof. Jing-yan Tang Shanghai Children's Medical Center.

The situation of children with cancer in Shanghai Region, China.

Shanghai is one of the Metropolitian in China with population of 16 millions (including 2-3 millions of mobiling population). Of them, 3 millions are children. According to the data from tumor registration in Shanghai, the incidence of childhood cancer between 0-14 years age is 109/million. So, we can estimate the annual new cases in Shanghai should be 300. Of course, the main form of cancer is acute leukemia.

A medical insurance system for children with severe illness has been established over 10 years in Shanghai (including Leukemia, Aplastic Anemia, Congenital heart diseases, Renal failure, Various causes of shock, etc.). The medical insurance premium for each child is about 50 Yuan (RMB)/per year (US\$6/year). If they have severe illnesses as mentioned above, they will be covered up to 100,000 RMB per year. If they require hematopoietic stem cell transplantation, additional 50,000 RMB/per year can be provided. So, now in Shanghai, almost 95% of the children with cancer can get appropriate treatment.

There are now 3 children's hospitals with about 100 beds for pediatric Hematology/Oncology. Under the leadership of the Chinese Medical Association Shanghai Branch, a collaborative children cancer study group has been established with standardized diagnostic criteria and treatment protocols: so the long-term Disease Free Survival for ALL is approximately 70-75%, and is 70% "CCR" for B-NHL. Over 1000 children with cancer, mainly for children with Leukemia have been cured in recent 2 decades. Under the auspice of the Shanghai Municiple Government and Chinese Communist Party as well as with the great coordinately efforts of the medical personnel, they have tried their best to investigate the pathogenesis of the childhood cancer in Shanghai Region, the individualization of the treatment to improve the cure rate and with the hematopoietic stem cell transplantation to treat some high risk and refractory or relapsed patients.

We are very happy to know recently this medical insurance system has been gradually adopted step by step in big or medium size of cities, such as in Beijing, Nanjing. So the future for children with cancer in China will be bright.

Announcement of scientific meetings in Asia

1. 4th Chinese National Pediatric Oncology Meeting: The meeting will be held from

September 8-11, 2005 at Tienjen, China. All SIOP members are welcome to join the

meeting and present paper. Interested members, please contact:

Prof. Yao-ping Wang

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2. 2006 4th SIOP-Asia Conference: The meeting will be held in April 6-8, 2006 at Shanghai,

China. The chairman of the Organising Committee is Prof. Yao-ping Wang. The deadline

for abstracts will be end of September 2005. Shanghai is one of the metropolitans of

China with flights connecting all the big cities all over the world. The weather in April is

nice, with 20-25°C. Shanghai is also a safe city. For further information, you may contact

the organizer at:

E-mail: siop_asia_2006@yahoo.com

Fax: +86-021-58393915

3. 2007 International SIOP Conference: The 2007 SIOP meeting will be held in Mumbai,

India. This is the first SIOP meeting decided by the Executive Board of SIOP rather than

by the general ballot of all the members. The new selection method has the advantage

that the favourite tourist place may not be selected just on the basis of attractive spots.

The Board will select a venue that will benefit more members such as less expensive

hotels and registration fee, so more members from less developed countries can afford

and attend.

SIOP 2007, Mumbai, India, 1st - 4th November, 2007.

For further details contact:

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4. 2008 5th SIOP-Asia Conference: The meeting will be held in Oman and Prof. Zakia Al Lamki & Prof. Mathew Zachariah are the organizer for the meeting.

Venue: Al-Khod, Sultanate of Oman

For more information, please contact:

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If members are aware of any paediatric oncology meetings to be held in Asia, please let the Editor know (e-mail: ckli@cuhk.edu.hk). We will try to disseminate the information to members in the Continent.

Children's Cancer Foundation (Hong Kong)

Introduction by Editor:

The Hong Kong Children's Cancer Foundation (CCF) was set up in 1991. Through the generous donation from the public, CCF has made tremendous contribution to the cancer service and development in Hong Kong for the past decade.

CCF firstly started with psychosocial support programme for patients and families. Other than financial support for purchasing equipment, sponsoring expensive medications, the Foundation also sponsored Hong Kong doctors and nurses to overseas training. For the past few years, CCF also sposnor doctors and nurses from Mainland China coming to Hong Kong for training in paediatric oncology. Recently, the Foundation also approved the sponsorship of a project to start a paediatric oncology training workshop in less developed area of China. The following message will have a brief introduction of the history, and also the services being provided by CCF. Hoping that through sharing of CCF experience, similar Foundation or organization can be set up in other counties in Asia, and this will benefit the patients and their families.

From the first days ...T

In June 1988, three-year-old Don-Don was diagnosed with leukaemia and admitted to the Children's Cancer Ward of the Prince of Wales Hospital in Shatin. As the child fought his battle with the disease, his mother kept a daily bedside vigil. It was from those days that the seeds of the Children's Cancer Foundation (CCF) were sown.

In the spring of 1989, Don-Don's mother, together with a group of dedicated doctors, nurses, parents of children with cancer and concerned individuals, formed a committee that was subsequently inaugurated in November of the same year as the Children's Cancer Fund for the Chinese University of Hong Kong with Lady Ford its patron.

In the early days, the Fund served only the Prince of Wales Hospital (PWH) – the Chinese University's teaching hospital. Generous donations enabled the Fund to employ a clinical psychologist and two counselling nurses to give direct services to the child cancer patients and their families. In recognition of the therapeutic effects of play, CCF introduced playwork in hospital. It pioneered the first play area in the PWH's child cancer ward. It established a Parents' Club and organized social functions for patients and their families to foster better understanding between parents and CCF, and for parents to provide mutual support. CCF also helped PWH to set up its Paediatric Bone Marrow Transplant Unit in 1991 with donation of US\$0.6 million as a start-up subsidy.

It soon became obvious that providing help to only one hospital was not enough. In November 1991, the Children's Cancer Fund became independent of the Chinese University and was renamed and inaugurated as the Children's Cancer Foundation.

... to the present

Today, the Foundation serves child cancer patients in Hong Kong's major public hospitals, particularly Prince of Wales, Queen Mary, Queen Elizabeth, Princess Margaret and Tuen Mun hospitals. Its mission vows to improve the quality of life for young cancer patients and their families in caring for their physical, psychological and social well-being, to help doctors improve the survival rate of children with cancer, and to assist major public hospitals in Hong Kong to upgrade equipment and services in paediatric oncology.

A Family Service Centre was set up in 1993, CCF delivers its core patient service, including clinical psychological service, family counselling, playwork, palliative and home care, long-term follow-up care, as well as financial, social and educational support.

After the first paediatric bone marrow transplant was carried out in 1991, CCF began its half-way home programme for children with cancer. With flats leased from the Government, CCF created a quasi-hospital environment for convalescing patients. At present, all three homes are set up in locations close to the major public hospitals for the use of those patients who have undergone intensive chemotherapy and bone marrow transplants.

The opening in 1995 of the Lady Pao Children's Cancer Centre in Shatin saw the dreams of CCF realized as it had appealed since 1989 for premises to be specially built for treatment of childhood cancer. During its construction, CCF took on the work for the design and furnishing of the Centre so as to create a caring, comfortable and cheerful environment for the patients. In the Centre, CCF maintains a Family Service Sub-office to provide frontline patient service that includes counselling, playwork and play therapy.

Children who survive their battle with cancer may suffer long-term effects from their encounter with the disease and its treatment. Since 1997, CCF has provided funding and resources for establishing long-term follow-up care for these patients. Continued monitoring of the cancer survivors will increase doctors' knowledge and understanding of the effects of this disease in adulthood.

In 1999, CCF launched the palliative and home care service that caters to children in the advanced stages of the illness. Working in close association with the attending doctors, CCF's team of specially-trained nurses works around the clock to make sure those patients have quality days at home, their suffering and discomfort reduced to a minimum, and in their last hours, a peaceful and dignified departure. This service creates a privacy option for patients and parents, reduces the inconvenience in travelling for treatment and, at the same time, relieves the burden on hospital resources.

As part of its hospital service programme, CCF has since its inception provided funding for the public hospitals to purchase state-of-the-art equipment and to train medical personnel. Since 1999, an annual grant of US\$0.13 million is awarded to enable doctors in the field to pursue research in paediatric oncology that will ultimately benefit patients as well as contribute to academic and professional advancement in childhood cancer.

Through its public service programme, CCF has succeeded in raising awareness of the disease. It participates in public exhibitions, publishes books and leaflets on childhood cancer, produces video documentaries and a half-yearly Chinese newsletter, gives lectures to schools and the public and promotes its work through the media and the internet.

In its role in providing important services to children with cancer, the Children's Cancer Foundation will continue to expand its scope of work to meet the needs of these patients in an ever-changing society.

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Minutes Of General Body Meeting Of SIOP Asia Held During Annual **SIOP Meeting** Oslo, September 17, 2004

Dr Rashmi Dalvi Secretary, SIOP Asia (2001-2004)

The meeting was attended by: Dr BR Agarwal, Dr R Dalvi, Dr W Wang, Dr MR Lokeshwar, Dr A Sachdeva, Dr A Borkar, Dr M Chaphekar, Dr P Kusumakumary, Dr JJ Seo, Dr F Bessho, Dr K Saha, Dr P Chitalkar, Dr M Alebouyeh, Dr S Choi, Dr LS, Arya, Dr S Kanvinde, Dr CH Chui, Dr AS Jacobsen, Dr CR Shi, Dr T Iehara, Dr Y Kawahara, Dr H Hosoi, Dr S Banavali, Dr M Kaneko, Dr Sutaryo, Dr S Mulatsin, Dr J Tang, Dr P Sobti, Dr P Kurkure, Dr N Singh, Dr V Jain, Dr A Mahajan, Dr T Seth, Dr A Nakagawara, Dr CK Li.

- 1. Dr B Agarwal welcomed the attendees and asked for comments on the annual report. Members were updated on the proposal for associate members. This had been put up & was under consideration with the SIOP board. SIOP Asia was progressing well with 3 biannual meetings & 2 newsletter issues behind us. Dr Wang was congratulated on having won the election for the post of SIOP President. Dr BA said that SIOP had very kindly accommodated all SIOP Asia related material on its website. A database of paediatric oncologists in Asia was being prepared pending information of other working/active members of the paediatric oncology fraternity & PHO organizations in various countries. There was a need for developing parents groups & networking to foster regional networks. Finances were at a zero balance presently, however a corpus could build up further with contributions from SIOP Asia meetings. SIOP board had also agreed to split its continental contribution for Asia into 4000USD for the continental meeting & 1000USD for publication of the newsletter.
- 2. Dr MR Lokeshwar outlined some of the problems faced in bringing out the newsletter finances for publications was one & the other was getting in contributions. Dr Banavali suggested that costs could be brought down by having an e-journal & sending it online. Dr R Dalvi & Dr A Sachdev thought that members could receive an e-copy but some prints were important for distribution to increase awareness & widen the net of SIOP Asia. Dr P Kurkure added that periodic e-copies with annual compilation of 2 volumes would cut down postage costs. It was then concurred that the newsletter should be sent electronically & if there was finance, then to publish it.
- 3. Dr Mannan was lauded in absentia on having carried through a very successful meeting. Dr BA mentioned that the local organizing committee had sponsored 150 scholars & fellows to attend the meeting. The conference also made way for public awareness & political publicity for the cause of childhood cancer through local media. The organising committee is requested to submit the accounts and forward the amount equivalent to 10% of registration fees collected at the conference.

- 4. Dr Wang was invited to form the SIOP Asia executive committee. Dr Jing Yan Tang (China) was nominated Secretary, Dr Chi Kong Li, Editor. Dr Bharat Agarwal & Dr Rashmi Dalvi would continue as ex officio executive committee members. The other members nominated were Dr Fumio Bessho (Japan), Dr Zakia Lamki (Oman), Dr A Sachdev (India), Dr. S Choi (Korea), Dr Sutaryo (Indonesia), Dr.AA.H.Pour Feizi (Iran) & Dr. Cheng-ren Shi (China).
- 5. Dr Wang thanked everyone for having elected him. He discussed the progress in planning the next SIOP Asia meeting to be held at Shanghai in 2006. He had brought down the costs by holding the meeting in the hospital facility itself. He discussed plans for the scientific programme which would be over 3 days (Fri-Sun). He planned to invite speakers from western countries, Asian countries & Chinese doctors. Dr Sutariyo suggested that the program could include discussion on the role of traditional Chinese medicine in cancer & cancer registration. Dr Kanvinde suggested having a website tailored to accept online registration & abstract submission. Dr Sachdev suggested as before that 1/3 faculty should be western countries, 1/3 other Asian countries & 1/3 from China. Dr Choi suggested having a symposium bringing out Asian characteristics of pediatric oncology eg SE Asia has a high incidence of retinoblastoma. He also offered to host the SIOP Asia meeting in Korea in the next available slot. Dr Kurkure asked for a slot for SAARC presentations. Dr Li said that the pro gram should balance out interests & needs of underprivileged & underprivileged nations. Dr K Sah asked that scholarships be arranged for those who would need them. Dr Sachdev pointed out that we need to develop other regions in Asia & foster twinning within the Asian region. Dr BA suggested that pre-conference workshops for postgraduates, fellows & nurses could be held. Members hoped that registration fees would include meals. Dr Wang said that registration for local doctors, students would be slightly subsidized as required. He also added that their Japanese counterparts had promised to contribute to the needs of the meeting.
- 6. Dr Kurkure made a presentation on the workshop held at Nepal as the beginning of Activities in the SAARC region. It was a well attended & successful venture. It was decided to continue Dr Kurkure as SAARC coordinator for another term.
- 7. Dr BA informed that SIOP 2007 slated for Asia had 2 bids from Hong Kong & India & the SIOP board had just informed the decision in favour of the meeting being held in Mumbai in the fall of 2007.
- 8. Dr P Kurkure put on record commendation of the hard work & enterprise of the outgoing President & executive committee

We must thank the Children's Cancer Foundation (Hong Kong) for the generous support to cover the expenses of publication and mailing of the Newsletter for the coming 3 years.

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