

SIOP-ASIA NEWS



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“Childhood Cancer is Curable”, Let’s build on our past

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From the Editor

Management of childhood cancer is multi-disciplinary approach including doctors, nurses and allied health workers. The input from the parents, families and the societies are equally important. Government support of course is essential for the development of cancer treatment but the non-government organizations can also play an important role in the development especially in resource poor countries. Palliative care for cancer patients is better developed in the adult settings. However children suffering from terminal cancers are also in great need of the palliative care. The above issues have been included in the recent Asian SIOP meeting held in Shanghai April this year. It was a very successful meeting with participants from many countries in Asia and outside Asia. More important is the participation of parent organization and separate nurse sessions, this make the meeting really a multi-disciplinary conference. The reports from some of the session chairs and the encouraging fruitful development after the meeting are shared in this issue of newsletter.

The newsletter is to serve the members of SIOP in Asia. I would encourage members or friends to submit articles related to childhood cancer in the continent to the editor. We will disseminate the information to members in the continent. SIOP is going to change the constitution in the coming annual meeting this September. The change will make the admission of membership more easy and hopefully more colleagues in Asia will join the SIOP in future.

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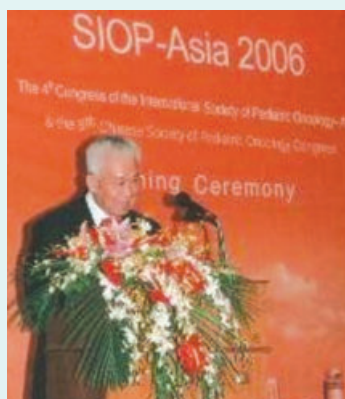


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President, Dr. Yao-ping Wang;
Editor, Dr. Chi-Kong Li (from left)

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Report from the President: A Special Report on SIOP-Asia 2006 Shanghai Meeting



The Congress President, Prof. YP Wang, addressed the delegates in the Opening Ceremony.

Prof. Yao-ping Wang

President, Fourth SIOP Asia Conference

President, SIOP Asia

Dear SIOP Board Members, members of SIOP-Asia and Friends all over the world:

On the occasion of the nice spring sunshine and flower blossom, with the leadership of the SIOP Headquarter and strong support from all the SIOP-Asia members, the Chinese Pediatric Oncology Society, Chinese Anti-cancer Association, Shanghai Branch of the Chinese Medical Association, JiaoTong University, Chinese Government and friends all over the world, the Forth Session of SIOP-Asia 2006 Shanghai meeting was successfully held on April 6-8, 2006 in Shanghai, China. There were 95 overseas delegates from United States, Canada, Germany, Britain, Switzerland, the Netherlands,

New Zealand and Australia. Of course, there were also many SIOP-Asia members from including Japan, Vietnam, Republic of Korea, India, Indonesia, Singapore, Bangladesh, Oman, and also Hong Kong and Taiwan. About 100 Chinese pediatric Hematologists and Oncologists joined this meeting. Over 156 papers were presented in this meeting. World famous experts were invited to make the key-note speeches including Prof. Ching-Hon Pui, Raul Ribeiro, BN Rao, Daniel Green, Ching C Lau from U.S.A., Prof. Martin Schrappe and Rupert Handgretinger from Germany, Prof. Anjo JP Veerman from the Netherlands, Prof. Peter Wagner and Jack Plaschkes from Switzerland, Prof. Michio Kaneko from Japan, and Prof. Yao-Ping Wang, Chi-Kong Li and Long-Jun Gu from China have made over 10 Key-note speeches. These lectures covered areas in Recent Advances in the treatment and research on different childhood cancers such as acute Leukemia, Non-Hodgkin's Lymphoma, Wilm's tumor, Hepatoblastoma, Neuroblastoma, Osteosarcoma, and also introduced new concepts and treatment measures on these cancers to the participants from Asian Countries. This greatly promoted the future development in research, diagnosis and treatment for childhood cancer in Asia, and plays very important role in improving the efficiency of diagnosis and treatment as well as quality of life. So, all the participants have got very memorable experience from this meeting. Besides, the great variety in the presentation, the conference also tried to solve the difficulties facing in the clinical practice and research in our locality, and this was the another characteristics of this meeting. Other than key-note speeches from developed countries, there were also a number of oral presentations and poster presentations from developing countries. There was special panel discussion on some difficult cases in the multidisciplinary team work discussion which attracted great attention from the participants. In addition, the experts from all over China and Asia also made presentations on the development in fighting against childhood cancer in their countries that further deepened the mutual understanding. At the same time, The International Nursing committee and the International parents committee also held the meeting to introduce their experience and promote the establishment of the parents committee in Asian Countries.

As the Representatives of the SIOP Headquarter, Prof. Bharti Agarwal, Anjo Veerman, Daniel Green and Hans Peter Wagner joined this meeting and monitored the full process with great satisfaction.

So, this was really a very fruitful and memorable meeting for all participants.

SIOP Asia 2006 Conference, Shanghai, China

The 4th SIOP -Asia conference was successfully held on 6-8, April 2006 in Shanghai. The theme of the conference was 'Recent Progress in Childhood Cancer'. There were about 150 delegates coming from China and 150 delegates from other countries including Asia and outside Asia. The delegates included doctors, nurses, and parents. The Conference also provided scholarship to 10 representatives that included free registration and accommodation. The venue of the Conference was Guangda Convention and Exhibition Center, and is also a 4 star hotel. It situated at the city center and was easily accessed by public transport including subway. There were also a number of 2-3 star hotels within walking distance, and charged at about US \$30-40/day. Since many delegates came from resource poor countries, the low accommodation cost and easy access to the conference center facilitated more participants to join the congress.



The delegates discussed with the presenter about one of the poster.



Delegates attended one of the parallel session of the congress.

Scientific Programme

The Scientific Committee received about 200 abstract submissions. There were 3 parallel sessions of medical oncology, surgical oncology and nurses. The Scientific Committee had worked hard to select papers for presentation in the 3 sessions. Finally 65 abstracts were included as oral presentation and another 30 abstracts as posters. The Conference had invited world experts to give keynote lectures in the 3 day conference. A team of experts from St. Jude Children's Research Hospital gave a series of lectures, Dr. CH Pui discussed the pharmacogenetics of acute lymphoblastic leukemia, Dr. R Ribeiro talked on acute myeloid leukemia and Dr. BN

Rao demonstrated the benefits of limb salvage surgery of osteosarcoma. Dr. M Schrappe shared the experience of BFM strategy on treatment of ALL, and Dr. R Handgretinger introduced the new approach of haplo-identical stem cell transplantation. Dr. M Kaneko discussed the Japanese model of managing advanced neuroblastoma. Dr. J Plaschkes highlighted the recent advances of hepatoblastoma and the new SIOP liver tumor trials. Dr. D Green summarized the results of previous and ongoing NWT and COG trials of Wilms' Tumor. Dr. C Lau introduced the molecular study of osteosarcoma. Dr. AJ Veerman discussed on Dutch

experience of treating ALL and also experience with Indonesian collaborative groups based on economic treatment protocols. The local speakers from China were Dr. YP Wang and LJ Gu and they presented the Chinese approach to lymphoma and leukemia. Other than the above keynote lectures, there were presentations on various aspects of childhood cancers. During the conference, the participants had good opportunity to discuss about management of childhood cancer.

In addition to the above session for doctors, there were two parallel sessions for nurses and parents. Separate reports on these two activities are also included in this issue of newsletter.



The participants listened to one of the keynote speeches. Who was giving the lecture? Of course, not the experts appeared in the front rows of this picture.



The lovely children from Shanghai gave an excellent performance during the Opening Ceremony.



Press Release: Prof. Wang and members of organizing Committee met the press and arouse the public interest on childhood cancer

Social Programme

The opening ceremony was well attended by local and overseas delegates and parents. After the official speeches delivered by the Government Health Officials, SIOP Officials and Organizing Committee Chairman, it was followed by a very entertaining performance. A group of children from Shanghai had shown a series of dancing and singing performance. The excellent performance attracted great applause from the audiences. The following banquet also demonstrated the art of Chinese cuisine and the delegates enjoyed the dinner very much. The Organizing Committee also arranged hospital visits to the Shanghai Children's Medical Center. Of course, many overseas delegates did not miss the chance of having sight seeing in this rapidly developing city and the historical scenery surrounding Shanghai after the conference.

The Report for Nursing Session of the 4th Congress of the SIOP-Asia 2006

As a life-threatening disease, caring for childhood cancer is always one of the biggest challenges for nursing. In China, the childhood cancer is becoming the first cause for childhood death. With the evolution of the treatment of the childhood cancer, the prognosis is being greatly improved while the risks of complications is increasing, which requires oncology nurses higher level of competency for caring for children with cancer. Meanwhile, children with cancer and their family need higher quality of life, which requires oncology nurses wider range of competency of caring for children with cancer and families not only focusing on physiological but also on psychosocial perspectives. Hence, the communication and collaboration between regions or countries can promote the sharing the knowledge and skills of nursing and caring for children with cancer. The nursing session of the 4th congress of the SIOP-Asia, which was successfully completed on April 6-8, 2006 in Shanghai, has provided the platform for the communication and collaboration.

For this great meeting, over seventy hematology and oncology nurses and nursing educators from ten regions and countries attended the conference, including foreign guests from United States, India, and Hong Kong region of China. Five keynote speeches were provided by four famous experts of nursing, while 14 oral presentations and 6 poster presentations were communicated by participants from Asian regions and countries.

The nursing session of SIOP-Asia 2006 was centered on one theme, embracing what is new and controversial within the many challenging topics. The topics focused on the different research and experiences on preventing and caring the complications of chemotherapy, the advanced nursing techniques, palliative care, support for children with cancer and their families, and so on. The evidence-based presentations updated and promoted our



One of the presentation in the parallel nurse session during the Congress.

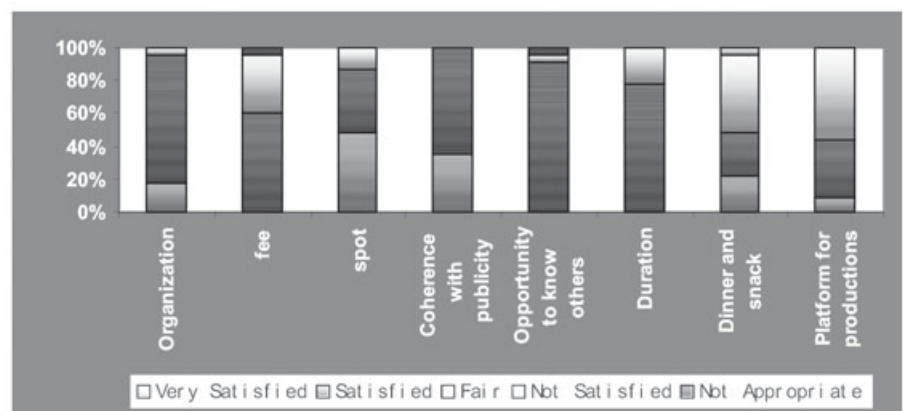
conception and knowledge, helping us share the valuable experience on the pediatric oncology nursing practices not only from the developed regions but the developing regions in fighting against childhood cancer. Almost everybody devoted themselves to the every speech and presentation through listening and discussing, resulting in professional and academic atmosphere for the nursing session. Therefore, most expressed their great satisfactions and appreciations on the quality of nursing session, especially for 4 keynote experts through our survey for nursing session of conference (see the survey below).

Even though this is the first time for us to organize and held such nursing session of international conference with few experience, we endeavored to create and maintain environment for study and communication, which made our guests feel comfortable and convenient while they were obtaining knowledge, sharing experiences, and making friends with others from different regions and countries. Most of our guests also showed their satisfactions on field, time arrangement, materials, and organization (see the survey below).

On the other side, there are several perspectives left for us to consider and improvement, such as, how to attend the multidisciplinary teamwork discussion with other health care providers for children with cancer, and how to establish the nation wide net work of oncology nursing, followed with international network, for more effective and efficient communication and collaboration of oncology nurses.

Caring for children with cancer and their families is developing towards the way, which is more professional and collaborative. Through communication and interactions in conference, we have not only widened our vision and deepened our mutual understanding, but also been building up a network, on which we could make great contribution to children with life-threaten diseases, helping them get rid of the shadow and disturbances of diseases, healing both their body and soul, and promote their growth and development for our future.

The satisfaction survey of the nursing session as follows



Report from SIOP Asia 2006 Nurses Committee

ICCCPO 2006 Asia Parents Meeting in Shanghai

Benson Pau

Chair of Organising Committee, ICCCPO Asia 2006 Parents Meeting

ICCCPO Asia 2006 Parents Meeting was held in Shanghai, China between 6th & 7th April 2006 in conjunction with SIOP Asia 2006 Conference. There were 76 participants from 12 regions / countries attended the two days ICCCPO Asia regional meeting; with 16 from greater Shanghai area, 14 from Guangdong province (South of China), 19 from Hong Kong, and 27 from other countries.

Objectives of the regional meeting were to:

1. reinforce the mission of ICCCPO “to share information and experience in order to improve access to the best possible care for children with cancer everywhere in the world” and particularly in Asia.
2. to strengthen connection between ICCCPO Asia members, and
3. to see what ICCCPO can do for the vast country of China with no formal local or national parent groups yet.

To achieve these goals, the 2 days programme included each of participating member / group to share their experience and activities, sharing session from medical professionals, interactive sessions between all participants and also solo interactive session of Chinese parents.

The meeting resulted in having 2 parent groups in China formed after the interactive session toward the end of meeting; with one in Shanghai region and one in Guangdong region. ICCCPO Hong Kong members will keep on offering support to the newly formed parent groups in China and expecting the relative SIOP members in China to offer support and co-operation too.

Also through the collaboration between SIOP Asia and ICCCPO members prior and during the ICCCPO Asia 2006 Parents Meeting, ICCCPO had strengthen a better link and working relationship with SIOP regionally.

We would like to take this opportunity to thank the volunteers from Hong Kong, the support of Shanghai organising team lead by Professor Wang - Chair of SIOP Asia 2006 Conference, the volunteers from Shanghai, and also the generosity of Shanghai Children Medical Center for the use the hospital conference center at no cost for the meeting on 7th April.

Further to the Shanghai meeting, we are glad to report that Shanghai parent support group has been officially formed in early June. Also Guangdong parents will be meeting with Hong Kong parents on 30th June in order exchange ideas of parent support activities. The meeting on 30th June will end up with a presentation by the parents at the 2nd Guangdong Province Paediatric Oncology Symposium. Thanks to the effort of SIOP-Asia to arrange the interactive session between parents and medical staff from Guangdong and Hong Kong. We sincerely hope that the continuous effort of SIOP-Asia and parents in Shanghai and Guangdong will contribute to better quality of life with the children with cancer and their families.



Parents from different cities of China joining the meeting



Parents from various Asia countries joined the discussion with help of interpreters.

Development of Paediatric Surgical Oncology in a Children's Hospital in Singapore

Dr Chan Hon CHUI

Consultant Paediatric Oncological Surgeon

Head, Department of Paediatric Surgery

KK Women's and Children's Hospital, Singapore

Introduction

Paediatric surgical oncology is the study of the surgical aspects of oncology in children. It not only involves the surgical management of solid tumors that need resection, haematological malignancies that require surgical procedures, it also involves diagnostic biopsies, vascular and enteral accesses, management of complications related to surgery, radiotherapy and chemotherapy. In recent years, some centers have included suspected paediatric cancers in its scope.

Over the years, we have developed Paediatric Surgical Oncology as a subspecialty within the Department of Paediatric Surgery at KK Women's and Children's Hospital with a dedicated paediatric surgeon trained in this field. I would like to share with you our experience.

History

Much of the history that is available came from the west. Before the era of chemotherapy and radiotherapy, surgeons and pathologists were the only doctors interested in the management of childhood cancers as early as the 19th century. This was even before there were paediatric surgeons. It was in 1960s that the paediatric oncologists assumed the leadership role in generating clinical trials therapeutic regimes. They accepted the responsibility for the management of children with unresectable or recurrent solid tumors and included them in chemotherapeutic programs and clinical trials. Paediatric surgeons in some

areas administered chemotherapy. Refinements in chemotherapy and radiotherapy subsequently allowed less radical and less mutilating operative interventions.

In Japan, a surgical cooperative group study of 403 paediatric patients with malignant tumors treated from 1963 to 1972 was reported by Dr M. Ischida. The Japanese Pediatric Surgical Society, led by Dr T. Ueda, appointed a committee on cancer in 1970. This was one of the earliest development of paediatric surgical oncology in Asia.

Paediatric Surgical Oncology in Singapore

Singapore had its humble beginnings in the 1960s. Paediatric surgery was performed by general surgeons until 1985 when the Department of Paediatric Surgery was started by Dr VT Joseph at the Singapore General Hospital. Paediatric surgical oncology was part of a general paediatric surgeon's responsibility as the resources were limited. In early 1990s, subspecialisation in paediatric surgery took place as more paediatric general surgeons returned from overseas training. Paediatric urology, paediatric hepatobiliary surgery and paediatric surgical oncology were developed. Dr Grace HN Tan was our pioneer who first developed paediatric surgical oncology into a subspecialty. Upon my return from a fellowship in paediatric surgical oncology at St. Jude Children's Research Hospital, I was able to better



appreciate the benefits of its development in our setup. We developed not only the clinical service, but also a training programme with clinical and laboratory research.

The development of paediatric surgical oncology moved in tandem with the development of paediatric oncology. The need for a dedicated paediatric oncological surgeon arose from the increasing number of patients with childhood cancers and the rapidly evolving paediatric oncology scene internationally. The last two decades saw tremendous amount of changes in the management of paediatric oncology. The use of preoperative chemotherapy and radiotherapy has made tumors more resectable. The use of diagnostic imaging techniques has also decreased the need for staging laparotomies in lymphomas. Multitude of clinical trials and protocols have already been tested and were in use. We saw the need to be updated on the surgical management of these patients and be able to provide appropriate input in a multidisciplinary team.

Debates of how a radical resection was integral to the success in treatment and how to achieve a sufficient margin for a tumor resection were important questions. The understanding of the biological behaviour of the tumor, the awareness of the effects of various chemotherapeutic agents, radiotherapy and other adjuvant therapies and their effects on surgery were crucial to the overall success of the treatment. Surgery after neoadjuvant therapy provided important information on the response of the tumor to

the therapy. In many ways, the responsiveness of the tumor to chemotherapy may also reflect on the prognosis of the disease and dictate the course of subsequent therapy.

The paediatric oncological surgeon cannot work in isolation and must constantly be in touch with the new developments in advanced techniques in paediatric general surgery. The application of endoscopic techniques is a good example in which several oncological surgical procedures may reap benefits from this new technique.

Applicability of this concept

The concept of a paediatric surgical oncology team or a dedicated paediatric oncological surgeon may only be possible in a hospital with several paediatric surgeons. Resources often do not permit one surgeon to concentrate on paediatric surgical oncology but he needs to be master of all trades. In many parts of Asia, there are more often centers with single paediatric surgeons who need to take care of all aspects of paediatric surgery, while in some, the general surgeon manages patients of the adult and paediatric age-groups. Training another surgeon for the purpose of subspecialisation may not be economically viable in such setups.

New discoveries and treatments are introduced everyday. Paediatric oncology is developing rapidly in many parts of the world. In a considerably privileged scenario, there would be a dedicated paediatric surgeon who takes interest in surgical oncology and would take on the responsibility of developing paediatric surgical oncology of the center, whilst he still continues with general paediatric surgery. Only in rare centers can a paediatric surgical oncology department be set up. The development of paediatric surgical oncology in Asia is an attractive and exciting. There are already many centers in Asia with paediatric oncological surgeons. These surgeons and those who are interested in paediatric surgical oncology should meet on a regular basis to update each other and to share experiences with the aim of benefiting our patients. Biennial SIOP-Asia and annual IPSO conferences are examples of such meetings.

Palliative Care

Editor: With the great success of treatment of childhood cancer, the cure rate is now over 70%. However we still have to face the 20-30% of children who fail treatment and get into the terminal phase. The palliative care in children with cancer is less developed as compared to adults. The small number of children with terminal cancer makes the development difficult. Below is a message from a nurse specialist dedicated to palliative care of children with cancer, and she shares her experience in the field.

Palliative care for children with cancer: Hong Kong perspectives

Lin Kwok Yin, Molin, Nurse-in-charge, Palliative and Home Care Service, Children's Cancer Foundation, Hong Kong

In Hong Kong the incidence of childhood cancer is about 150 per 1,000,000 children. Similar to Western countries, childhood cancer is the number one cause of death amongst children between the ages of 1 to 14 in Hong Kong.

Since November of 1999, the Children's Cancer Foundation (CCF) has initiated a Palliative and Home Care Service, which cares for 70% of children in the advanced stages of cancer in Hong Kong every year. CCF is a charity organization in Hong Kong, which is well supported by public donation. All services provided by CCF to its clients are free of charge. The target group of its patient services is children with cancer who are under the care of five major hospitals under the Hospital Authority in Hong Kong.

The goal of the Palliative and Home Care Service is to provide specialized palliative nursing care for children with incurable cancer, thereby enhancing their quality of life. Palliative care uses a family-centred approach. The child and his family are treated as one unit of care. The care and support given to the patient is based on the belief that every day of human life is precious and meaningful,

and that every human being deserves dignity and concern from others.

The mission of the palliative nursing care team is to provide the best physical and emotional comfort for the child and the family. There are three nurses on the team who, in cooperation with other professional workers in CCF and various disciplines from the five attending hospitals, refer the patients to this service. The home care nurse assists the family to take care of the child by teaching and supervising parents in procedures and techniques needed to provide comfort to the child. Through frequent telephone consultations, the nurse is able to update and monitor the patient's condition and give advice to the family as and when necessary. Thus the child is able to remain at home as long as possible and stay in hospital only when it is absolutely necessary. Home care nurses are always available to handle any problems that might arise and can provide supplies and equipment needed for the quality care of the child. The family can also seek advice from the nurses on how to care for the dying child in a way that is most compatible with their chosen lifestyle.

Regarding the psychological aspect, an open, honest discussion with children who are over 4 years of age is possible. Traditional Chinese culture makes it uncomfortable for Chinese people to talk about death openly. One of the roles of palliative nurse is to facilitate an open discussion about the impending death with children and their parents. These heart-to-heart conversations have a deep effect on the family. It enables the vast majority of children and their families to spend their last days together, creating final memories, giving final gifts, finding spiritual peace, and saying goodbye. It is helpful for family's bereavement.

The majority of children, in fact, do wish to stay at home until the end. This allows them to enjoy more autonomy, privacy, and a greater sense of normalcy and control over their daily activities, as they have fewer restrictions and do not have to follow the routines of the ward. Spending their last days, weeks, or months at home not only benefit the dying child, but it is also believed to be crucial to the well being of parents, siblings, and other family members who most surely suffer greatly as well.

Home death is not promoted per se, but a child and his parents will be fully supported if it is their wish. In the past, parents were put through a quite unpleasant ordeal when the body of their child was sent for a certification of death at a hospital. CCF intervenes as much as possible during negotiations with the Hospital Authority to insulate parents from the unpleasant and emotionally charged process. The procedures of death certification when children plan to die at home have been simplified as of

April in 2005. Bereavement care is provided for the family after the child's death. Memorial programmes and bereavement groups are organized to support the families and help them get through this difficult time. For a more personal approach, individual follow-up visits and support are also offered by the home care nurses.

Supporting a child staying at home until death has been challenging and distressing for home care nurses. Witnessing a child's physical pain or mental distress is one of the major stressors for home care nurses. Nurses must be mindful not to become enveloped and trapped in the families' stress and despair, and develop a sense of powerlessness. Therefore, the support within the team, and some additional time off, are necessary and important to maintain the mental well being of palliative home care nurses. However, the experience of working together with children who are terminally ill and their families is precious and worthy. Every story of a patient and his family at the end of life is unique and contributive to the experience of palliative home care service.

Because of inadequate funding, palliative care for the children of Hong Kong is not comprehensive. There is no palliative care for children with other types of life-threatening illness in Hong Kong. This situation requires further research because there are still many societal needs in Hong Kong that are not being addressed. To be more specific, studies on terminally ill children and their families are needed for the development of new services to help them at a time of great need.

References

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- S.T. Tang. Taiwan perspectives in palliative nursing care. In B.R. Ferrell & N. Colye (2001). Textbook of Palliative Nursing. Oxford: New York.

Coming Pediatric Oncology Meeting

1. 38th Congress of the International Society of Pediatric Oncology:

Date: September 17-21, 2006

Venue: Geneva, Switzerland

Contact: Sandrine.haemmerli@mci-group.com

Website: www.siop.nl/siop2006

4. International Conference on Childhood Cancer (ICC)

Date: October 29-31, 2006

Venue: Tehran, Iran

Contact: alireza.mosavijarrahi@gmail.com

2. ASPHO 2006 Pediatric Hematology/Oncology Review Course

Date: October 13-16, 2006

Venue: Rosemont IL, USA

Contact: info@aspho.org

Website: www.aspho.org

5. 39th Congress of the International Society of Pediatric Oncology

Date: October 30 - November 3, 2007

Venue: Mumbai, India

Contact: siop2007@varriance.com

Website: www.siop2007.in

3. ESO Masterclass in Paediatric Oncology

Date: October 14-18, 2006

Venue: Orta San Giulio, Italy

Contact: masterclass@esoncology.org

Website: www.cancerworld.org.eso

6. 5th SIOP Asia Conference

Date: 2008

Venue: Al-Khod, Sultanate of Oman

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