

## Report from the president

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After 11 years this will be my last contribution to the SIOPO Newsletter. I was on the Board first as Secretary General and then President and I can honestly say that it has been a truly wonderful time. At the Hamburg meeting in 1991, Pat Morris Jones, an ex president, came up to me and suggested that it was time I took a greater part in SIOPO and would I like to stand for election. Up until then my visits to the SIOPO Annual meeting had been somewhat erratic since my first one in Lisbon in 1979. However, I have now been fortunate enough to attend all since San Francisco. There are many wonderful memories of both the scientific and social programmes. Perhaps the most important is that the SIOPO annual meeting has become the premier international paediatric oncology event of the year. There are now many disease specific meetings e.g. brain, leukaemia etc. but our annual meeting is the only event to give an overview of all recent advances. Up until now we have had special themes as well as general papers but we are now moving towards a more general programme.

Several years before I really became involved it had become clear that a large part of our efforts must be devoted to paediatric oncology in the developing countries. At least 80% of the world's

children who are unfortunate enough to develop cancer had no access to curative treatment. Indeed even palliative care was almost not on the agenda. Our efforts for PODC are now really bearing fruit. When I became President I said that one of my main aims was to abolish PODC or at least the concept. Only when our mission is clearly to help all children with cancer will we be able to say that we are really doing our job. I am delighted that in the Cairo and Oslo meetings we have been able to integrate the "PODC" papers into the main meeting. The standard of papers have risen enormously and the messages coming from economically less advantaged countries are important for us all to hear. Of course the annual meetings are but one part of our activities and the inspirational work of Bharat Agarwal and his colleagues in India and Peter Hesselning in sub Sahara Africa, show what can be done in the educational and therapeutic fields. I think we are now playing a significant part in the globalisation of treatment for childhood cancer. Our mission must remain to bring cost effective therapy to as many children as possible.

Now please allow me to reminisce a little about the social highlights of the past few years.

- *San Francisco* - I remember the reception in the earthquake museum feeling what it would have been like to experience a major earth tremor. Running over the Golden Gate Bridge was truly memorable. This was really the start of the SIOPO "Fun" runs which persist to this day.
- *Paris* - Jean Lemerle and his team organised an excellent meeting in a huge conference centre. The dinner for over 1000 seated guests was a phenomenal feat of organisation.
- *Montevideo* - SIOPO's first visit to South America had so many highlights. The most memorable was to arrive 2 days early and find that the conference centre was still being built. We were assured that in 48 hours it would be fine – and so it was. The annual dinner was held in a food market where we could sample various delicacies as well as dancing and music. A photograph of Tom Voute dancing with a daffodil in his mouth has already appeared in the Newsletter. Luis Castillo was a truly wonderful host.
- *Vienna* - was memorable for the fun run in the early morning ethereal ➤

**ANNOUNCEMENT TO ALL MEMBERS**

**HAPPY SUMMER HOLIDAYS!!**

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mist of the Schonbrun Palace and for being taught to do the Waltz in the City Hall.

- *Istanbul* - on arrival we were shown the Bosphorous Bridge linking Europe and Asia. Unfortunately we could not run over this as it was closed to foot traffic because of the suicide risk. The annual dinner was held in the Military Museum complete with belly dancers.
- *Yokohama* - was a very different experience. The meeting itself was excellent but in a totally different cultural setting. This was a wonderful experience for us all.
- *Montreal* was a joint meeting with ASPHO and is an experience we should try and repeat.
- *Amsterdam* - a very well organised meeting which was a tribute to Tom Voute's ability. Queen Beatrix joined us for one session and we heard a brilliant lecture about the possibilities

opened up by the genetic sequencing of the tiny nematode worm.

- *Brisbane* - the long trek was well worth it and I was persuaded, against my better judgement, to ride the bucking bronco which of course was caught on camera for the newsletter.
- *Porto* - was memorable for the daily bus trip to get to the conference centre but I hope that some of us made new friendships which have endured.
- *Cairo* - I should have learnt from my errors in Brisbane as I, along with Kathy Pritchard Jones, rode into the annual dinner on a camel.

Now we are on our way to Oslo and I know that Sverre Lie will have something very special organised for us. The scientific programme is excellent with good review/guest lecturers and many excellent free papers. The Continental meetings have also been

memorable from India to the Ivory Coast. In Africa we have perhaps seen most progress. At the first meeting we were told what could not be done. Now we hear what tremendous things have been achieved in spite of limited resources.

Finally I have worked with some wonderful fellow officers and of course the last few years have been a delight working with Rosalinde Kennis.

So now I pack my bags and ride off into the sunset. Handing over to Tim Eden reassures me that the good work of SIOP will continue. We need to elect a new President Elect, Treasurer and Secretary General. I urge you to put your name forward. It can be hard work but it is enjoyable and very satisfying. We will meet in the future but in the meantime I thank you all for the support that you have given me in pushing forward a better chance for children with cancer, no matter where they might live.

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## Welcome to the 36th Annual SIOP Meeting in September 2004



Dear SIOP- and IPSO-members, parents, nurses and friends,

The 36th Congress of the International Society of Paediatric Oncology is coming here! We welcome you all to our country way up north. You will be at the 60° latitude!

A 100 years ago the Nordic countries were amongst the poorest in Europe. Today it is very much the opposite. You will enjoy visiting a country where few have too much and few have too little (at least until recently). Oslo has grown significantly during the last decades and is today a cosmopolitan city with a beautiful waterfront and a lot of recreational possibilities. ➤



I hope that you will feel you are in a friendly city in a friendly and very privileged country.

The venue we have chosen has never been used as a congress arena before. I hope you will enjoy the mixture of Concert Hall, Cinemas and Art Galleries. Every event is within walking distances from your hotel.

On Saturday morning there will be a moderate "Fun-run-event" through our beautiful Vigelands Park with the famous sculptures of Gustav Vigeland.

The weather can be very pleasant in September but it can also be rainy and cold. This is beyond the control of the local committee!

I hope that we will share exciting days full of scientific and social pleasure. I hope you will be intensely participating, discussing and making new friendships. I hope you will go home utterly exhausted. When strength recover, you will find that you have charged your batteries and are better off fighting childhood cancer than before the meeting in Oslo.

**Prof. Sverre O. Lie**  
**Chairman of the Local Organising Committee SIOP**  
**2004 - Oslo**

Many will ask why we have chosen the Viking ship as our logo. Admittedly one reason was that it looked nice. In addition it is a symbol. Today SIOP is a strong organisation and we would like the Viking ship to symbolize strength and courage, curiosity and adventure. It is recommended that you forget the more nasty stories about the Vikings.

You will find the program very exciting. I am very much impressed by – and grateful to - Kathy Pritchard Jones, the chairperson of the Scientific Committee. She and the other members of the committee have done great efforts in bringing this program together. We are grateful to all keynote lecturers and symposia organisers who have accepted to participate in our meeting.

A special welcome to the nurses, who likewise have gathered a very exciting program. The International Confederation of Cancer Parent Organisations is also heartily welcome to Oslo.



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## **Announcement by the SIOP 2004 congress organisers:**

### **Correction**

On page 35 of the preliminary programme it was wrongly stated that VAT is included in the registration fees. However, these fees do not include VAT as VAT is not applicable on the registration fees.

The fees as stated on the SIOP website and on the registration form are correct.

# Report from the Scientific Committee

This year has been a busy one for the Scientific Committee, with much discussion on the responsibilities of SIOPEL in attaching its name to clinical trials. This debate has been fuelled in part by the legislation imposed across the European Union from May 1st 2004, defining standards for all clinical research. These standards have been met for many years by the relatively well-funded North American groups. However, we now find ourselves having to address the quality of trials in childhood cancer around the world. Reassuringly, nearly every country has in place a procedure for ethical review of clinical research and a requirement for informed consent by research participants. It is the implementation and documentation of these that show some variability. The individual views of the Scientific Committee vary somewhat depending on their own national experience. However, we believe that SIOPEL still has an important role to play in facilitating collaborative research both within and between countries around the world.

The constitution was changed at the AGM in Cairo, 2003, to spell out that "SIOPEL is not a clinical trials organisation and does not have the organisation or structure to act as a sponsor of clinical trials". When one looks at the definitions of the role of a 'sponsor', it is clear that many of these responsibilities are already being met, at least in part, by committed physicians and their employing institutions at a national level. Indeed, each country usually has national legislation governing procedures for opening and monitoring clinical trials. We need to think creatively to overcome the 'knee jerk' reaction that it is safer to close down clinical trials. As a Society, we must ensure that the important questions that need to be answered to improve childhood cancer treatment continue to be addressed through clinical research.

SIOPEL wishes to encourage clinical studies and the Scientific Committee performs the function of peer review for submitted

protocols in order for them to carry the SIOPEL logo. Members are reminded that such requests for new protocols must be submitted to the secretariat well in advance of the Scientific Committee meetings in January, April and in the autumn at the annual meeting each year. The requirements for endorsement are those that are generally required for a protocol to pass ethical review at a national level. Namely, the trial must be well designed and adequately powered to answer the questions posed, there must be a robust scientific justification with comprehensive review of existing data, there must be an independent data monitoring committee and adequate means of reporting serious toxicities. In addition, the Scientific Committee must be sent an informative annual report to ensure that continuing SIOPEL endorsement is appropriate, and the protocol must carry a statement to the effect that SIOPEL is not the sponsor of the trial.

The enthusiasm for SIOPEL members to work together has already achieved much progress for children with cancer around the globe. Outstanding examples are the Burkitt lymphoma project, started in Malawi and now rolling out to other sub-Saharan countries in Africa, and the much larger SIOPEL liver trials, SIOPEL soft

tissue sarcoma (MMT), brain tumour and nephroblastoma trials, to name but a few. Updates on several of these will be presented in Oslo.

And so, to Oslo. The Scientific Committee, with the enthusiastic support of the Local Organising Committee, has put together a fabulous programme. There are 20 keynote lectures, of which the majority will be recorded with the help of the St Jude's Cure4kids website team, so that they can be made available on line after the meeting. This is an exciting new development for SIOPEL which, if successful, we aim to continue and even expand in the future. There are symposia addressing the 'key challenges' in seven disease types: acute lymphoblastic and acute myeloid leukaemia, Hodgkin's and non-Hodgkin's lymphomas, Langerhan cell histiocytosis and, jointly with IPSO, neuroblastoma and rhabdomyosarcoma. Many other aspects of paediatric oncology are also covered in plenary sessions, symposia and oral sessions. The whole of Saturday is devoted to reviewing progress in new drug development and the requirements to run international clinical trials. This theme is continued in the last session of the meeting, from 2-4 pm on Sunday, when we hope that you will all stay to contribute to the debate ►



The Scientific Committee in action selecting and placing all abstracts in the Oslo scientific programme

on the future of clinical trials in paediatric oncology and how SIOp can help.

We received nearly 800 abstracts. For the first time, we introduced an anonymised review process, with each abstract (minus authors and institutions) being scored independently according to a nine point scale by four members of the committee. Selection for oral or poster discussion presentation was made on the basis of ranking of aggregate scores: 150 orals, 70 poster discussion, 500 posters. As we saw in Cairo, the standard of submitted abstracts was generally high. Just under 10% were rejected, usually because of poor content or because the conclusions were not justified by the data presented. For only the second time, the Schweisguth prize has been awarded to a nurse, who is also a PhD student. Her study, entitled 'Care related distress in parents losing a child to cancer: a population-based long term follow up', should be of great interest to the entire membership and to the parents attending the ICCCP meeting. The Fasanelli family have kindly allowed

their support to be used this year to bring Professor Olivier Delattre, the discoverer of the molecular defect in Ewing sarcoma, to deliver a keynote lecture on target discovery in this family of tumours. The Nollenburg prize will be awarded on the usual competitive basis between two pre-selected oral presentations on the theme of bone tumours.

For those of you who have not yet decided to come to Oslo, I hope the above is sufficient to tempt you! You will not regret your journey to the land of the Vikings.

This is my last report as chair of the Scientific Committee. It has been an enjoyable if arduous three year term. I wish my successor, Giorgio Perilongo of Padova, Italy, every success in this role in the next few years. He will be working closely with our dedicated secretariat, run so efficiently by Rosalinde Kennis, to organise the next three meetings in Vancouver, Geneva and Mumbai. Finally, I cannot close without a special

word of thanks to the chairmen of the local organising committees with whom I've had the pleasure to work over the last three years. First, to wish Bernardo Sodres-Borges well in his retirement from full time paediatric oncology. I'm sure he has left his successors in Porto well placed to take forward his vision and hard work. Second, I must yet again thank Elhamy Rifky Khalek on behalf of us all for making the Cairo meeting such an intellectual and financial success. Through his efforts, the congress resulted in a modest profit, despite the negative forecasts, and we all enjoyed the wonderful Egyptian hospitality. Finally, Sverre Lie, whose work is not yet finished. It has been an honour to work alongside one with so much knowledge and wisdom about child health and such compassion for the future of children with cancer worldwide.

On behalf of the Scientific Committee, I encourage you to come to Oslo. For those not able to attend, I hope that you will enjoy our new web-based congress update. ■

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## REPORT

# from the Secretary General

The SIOp Board met on January 16, 2004 and April 21, 2004 in Amsterdam. Major issues discussed at these meetings included a review of the annual meeting in Cairo, selection of the abstracts to be presented at the annual meeting in Oslo, the sites for future annual meetings, nominations for Secretary-General, Treasurer and president-elect of SIOp, election of new members of the Scientific Committee, and the new journal (Pediatric Blood and Cancer).

Local organizing committees from Mumbai, India and Hong Kong, China presented bids for the SIOp annual meeting in 2007. Both bids were thorough and the local organizing committees gave ample evidence of skill and enthusiasm. The SIOp council, made up of the SIOp Board members and the continental presidents (with the continental president for Asia not voting due to the conflict of interest) voted by e-mail in

May 2004 and selected Mumbai as the site for the SIOp annual meeting in 2007. The site will be the National Center for the Performing Arts (<http://www.tata.com/ncpa/>). The council congratulates Dr. Bharat Agarwal and his local organizing committee and thanks Dr. Chi-Kong Li and his organizing committee for their interest and hard work in preparing the bid for Hong Kong.

The SIOp board will now consider bids for the SIOp annual meetings of 2008 and 2009. Originally the meeting in 2008 was to be held in Africa, Mexico, Central or South America. However the ECCO meeting will be held in 2009 (it occurs every other year). This would provide a significant conflict with the SIOp annual meeting that was to be held in Europe in 2009. As a result, the venue for the 2008 SIOp annual meeting has been changed to Europe, and that

for the 2009 SIOp annual meeting to Africa, Mexico, Central or South America. Please notify the SIOp Board, through the SIOp Secretariat ([secretariat@siop.nl](mailto:secretariat@siop.nl)) of your interest in submitting a bid after consultation with your colleagues and the appropriate SIOp continental president.

Elections will be held in December 2004 for the Secretary General and President-elect of SIOp. Please submit nominations to the SIOp Secretariat by November 1, 2004.

The revised Constitution and By-Laws were presented at the Annual General meeting of SIOp in Cairo, Egypt, and were approved by those attending the Annual General meeting.

I hope that everyone has a relaxing summer. I look forward to seeing all of you in Oslo in September. ■

# REPORT FROM THE TREASURER

## From the Treasurer: Congress organisation

Many members have asked: why are the SIOF congresses so expensive? I will try to elucidate some of the causes behind this. SIOF congresses attract between 800 and 1400 delegates. The total costs of the congress have to be met by the income: registration fees, proceeds of commercial exhibition and sponsoring and other income. Let me give a budget of a typical congress, derived from the budgets of the last 5 congresses.

Printed matter	60,000
Congress accommodation	160,000
Organisation costs	130,000
Office costs	50,000
Scientific Programme	120,000
Costs to participants	150,000
Scholarships	30,000
Exhibition	20,000
Various	30,000
TOTAL Expenses	750,000
Registration fees	550,000
Exhibition	50,000
Sponsoring	100,000
Other income	50,000
TOTAL Income	750,000

As you can see, the total income and expenses balance out at Euro 750,000 (US\$ 900,000 at current exchange rates). The costs of the congress accommodation are the major budget item, followed by costs to participants: from badges to coffee, meals, annual dinner (the main 'Other income' is the income from tickets for the annual dinner). Even with very much effort of the Board, the Scientific Committee, and not least, the Local Organising Committees, it has proven very difficult to attract more industrial income through the exhibition. Here, the fact that this is a medium sized congress, for a population of professionals with relatively few patients, and small ones at that, makes that we are apparently not very attractive to the pharmaceutical industry. Therefore, the congress budget relies mainly on the income from registration fees. If we are lucky, the expenses are lower than budgeted for, and the income is more than anticipated. Generally, the financial end result of a SIOF congress lies between minus 10% (the congress made a loss) and plus 25% (profit). More profit is not needed. However, a reserve is necessary. First to cover SIOF for big losses due to events that are uninsurable (war, terrorism, and natural disasters). Second, because every congress needs 'seed' money, that is, there are already expenses before there is any income. The bottom-line: if and when more exhibition income and sponsoring money can be obtained, the registration fees can come down. The Board and Local Organising Committee invest a lot of time and effort to try to attract financial support. Your treasurer does the best he can to contain costs. Not always a popular job. One of the measures to contain costs is to bargain harder (ourselves) for the most economical congress venue. From the

2005 congress in Vancouver on, SIOF will do more through our own secretariat, linking to local professional congress organisers. Congress has served us well from 2000 until 2004, but we think we can manage more economically and at the same qualitative level taking more in our own hands regarding the organisation of the congress, the abstract handling etcetera. As you can see from the budget, this may bring down the organisation costs, but the other budget items will not change. I would like to stimulate all members to help finding support for our Annual Congress, so that the registration fee will not be a reason to miss an excellent scientific and educational experience.

Anjo JP Veerman, Treasurer

## From the Treasurer: PODC activities

Not all members know that SIOF supports PODC activities financially. SIOF has a dedicated account for PODC activities, that is outside the budget itself. This account is fed (among others) by funds from WHO (Sverre Lie), National Cancer Foundations and various charities (HansPeter Wagner). Most of the funds provided are committed to a special project: for instance the India project for education in Pediatric Oncology, the Malawi (Burkitt Lymphoma) project and the Indonesian Wijaya Kusuma ALL project. Apart from that, at each SIOF Congress, SIOF offers a scholarship (from the congress budget) for 20 to 30 delegates from developing countries. Quite often, the local organising committee raises extra funds for fellowships. SIOF supports regional meetings in developing countries (SIOF Asia, SIOF Africa) with a donation of US\$ 5,000 per congress (from the SIOF budget) and on top of that, reimburses part of the costs of invited speakers.

Anjo JP.Veerman



# PODC NEWS

## PODC Committee Meeting in Oslo, Norway, at SIOP 2004

At the Concert Hall, Chamber Hall  
On Thursday, September 16, 12.30 - 14.00

To all Members, Consultants, Continental Presidents and Congress Participants:

The PODC Committee Meeting is open to all Congress participants.

There will be two parts:

12.30 - 13.00 the PODC Committee Business Meeting

13.00 - 14.00 Special Reports and Issues

We invite you to send proposals for the meeting agenda and/or the Special Reports and Issues section,

**not later than July 31**

to

HansPeter Wagner, MD.

Chairman of the PODC Committee

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Tel and Fax xx41 31 961 25 88

hpwagner@bluewin.ch

**We hope to see you in Oslo!**



Hans Peter Wagner-Chair of the SIOP PODC Committee

# News from the International confederation of Childhood Cancer Parent Organisation (ICCCPO)

1994-2004 – 10th Anniversary of the International Confederation of  
Childhood Cancer Parent Organisations (ICCCPO)



As the newly elected President of the International Confederation of Childhood Cancer Parent Organizations, it's a pleasure to report on the current status of the organisation and its plans for the immediate future. From its humble beginnings, ICCCPO can be proud of its continually growing membership. As of the last Annual General Assembly, there were 64 organisations from 52 countries. Moreover, the executive board is representative of all parts of the world which ensures the diverse needs and issues facing parent groups are being heard and addressed where practical.

One of the measures of ICCCPO's success has been the programs that have been established. These include the ICCCPO newsletter, the Annual Conferences, the Stipends Program, the Parents Helping Parents Fund, the International Childhood Cancer Day, the ICCCPO website and the Resource library. All of these programs have helped our members gain valuable information and support from each other.

ICCCPO drew up Guidelines for Standards of Care and promoted Early Warning Signs, both adopted by SIOP. The Health Professionals are an integral partner for ICCCPO. We have a wonderful working relationship with the International Society of Paediatric Oncology (SIOP) and we thank them for respecting and acknowledging the voice of parents in the treatment of Childhood Cancer.

Like many voluntary organizations, ICCCPO receives no governmental funding and relies on membership fees and sponsorships to be able to deliver its programs. The voluntary time and money spent by board members in attending Board meetings and undertaking the tasks of running the organization must not be underestimated. Volunteer services have been estimated at around USD 50,000 a year. My thanks go to all past and current board members for their contribution and dedication.

A special thank you goes to our two life members, namely Jesús Maria Gonzales Marín (Spain) and Gerlind Bode (Germany). The contribution by these two individuals has been

extraordinary, and we welcome their continued support. Looking ahead there are many challenges. The Board is committed to delivering more of the same programs that are currently in place. As funds permit we will endeavor to look at implementing new programs. These would include: establishing a more robust international survivors network and addressing the issues facing the increasing number of survivors. Development of regional committees and delivery of regional conferences would also go along in addressing the concerns facing specific regions. We have a strong commitment to working with the United Nations to ultimately ensuring every child suffering from Cancer can get access to treatment. In closing I am looking forward to the challenge of building on the work of my predecessors and making a difference to the lives of children suffering from cancer wherever they may be. I take this opportunity of also thanking all our members for their outstanding work and their participation in the journey towards achieving ICCCPO's mission.

**Simon Lala, New Zealand**  
**President ICCCPO**

#### **ICCCPO Executive Committee**

Simon Lala, New Zealand, chair  
Geoff Thaxter, UK, vice-chair  
Christine Wandzura, Canada, secretary  
Julian Cutland, South Africa, treasurer  
Edith Grynzpanchoc, Argentina  
Ira Soelimityo, Indonesia  
Irina Ban, Serbia&Montenegro  
Marianne Naafs-Wilstra, Netherlands, chair Oslo Conference  
Mark Chesler, USA

#### **ICCCPO Secretariat**

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# Childhood Cancer Foundation-Candlelighters Canada appoints new President/CEO

Toronto, ON - May 4, 2004

The Board of Directors of The Childhood Cancer Foundation-Candlelighters Canada is pleased to announce the appointment of David Stones to the position of President and CEO, effective May 11th, 2004. The Childhood Cancer Foundation is Canada's only charitable organization focused completely on childhood cancer issues, directing a strategic program of pediatric oncology research funding, advocacy and information support toward improving the quality of life for children with cancer and their families.

As a business and marketing/communications professional, David Stones brings to the CEO position an accomplished track record of executive leadership in each of the private, public and not-for-profit sectors, largely in the areas of health and finance.

Most recently, Mr. Stones held the position of Vice President, Marketing and Communications with Mount Pleasant Group of Companies, one of the country's largest providers of bereavement related services. Prior to that, David was National Director, Marketing and Communications for the Canadian Cancer Society/National Cancer Institute of Canada, where he also had responsibility for national revenue development for most of his five year tenure.

David's broad business experience, together with his applied knowledge of brand management, strategic relationship building, media and public relations, and fund development will serve the Foundation well as it seeks to build its influence base and profile across Canada.

David's understanding and appreciation of Canada's cancer control system will also be of immediate benefit to the Foundation in the pursuit of its business agenda. ■

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## REPORT FROM SIOP IN AFRICA

A successful 6th continental meeting was held from 3-5 May 2004 in association with PASPA in Blantyre - Malawi. The main theme was the challenge of care and the prospect of cure of children with cancer. The venue of the meeting which was attended by delegates from many African countries was beautiful Malawi Lake. This was another opportunity for many of our colleagues in Africa to meet on our own soil; there was active discussion of papers and discussion of possible approaches to therapy in countries with limited resources and also from excellent resources.

Professor M.Harif from Morocco, confirmed that the next 7th Continental SIOP meeting will be in Marrakech in Morocco in 2006. Also, delegates from Kenya and Ghana asked to host future meetings which is very good sign for the future.

### Vote of thanks

This is my last opportunity as continental president to sincerely thank the SIOP board and all my colleagues and friends who have encouraged and supported our dreams and attempts to better the outcome of children with cancer in Africa. Professor Fouzia Mesfer Alaoui will be the new president and she will take office at the OSLO SIOP meeting. Professor Mesfer is Professor of Pediatrics and Head of Department in the children hospital in Rabat, Morocco. She has devoted most of her

activities for the sake of children with cancer in Morocco, and she organized the 3rd continental meeting of SIOP in Africa, which was very successful.

**Professor Elhamy Rifky A.Khalek**  
Continental president of SIOP for Africa



Delegates from the 6th Continental Meeting of SIOP in Africa, held in Blantyre, Malawi



Elizabeth Molyneux (left),  
Peter Hesselting (middle) and  
Francine Tchintchime from  
Cameroon (right);  
the Burkitts Malawi Team

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## **REPORT FROM SIOP ASIA**

### **From the President, SIOP ASIA: Annual Report 2003-04**

**Dr. Bharat R. Agarwal**  
Head, Dept. of Pediatric Hematology-Oncology,  
B.J. Wadia Hospital for Children, Parel, Mumbai - 400 012.  
Email : [parul@bom5.vsnl.net.in](mailto:parul@bom5.vsnl.net.in)

The highlight of the year of course has been the 3rd SIOP Asia Conference held at Dhaka, Bangladesh in February 2004. I would like to place on record my deep sense of gratitude to all the members of SIOP Asia and the SIOP Board for their unstinted support.

#### **SIOP ASIA CONFERENCE 2004**

The third SIOP Asia Conference was held in Dhaka, Bangladesh from February 26-28, 2004. E-mail: [pead@bangla.net](mailto:pead@bangla.net) This conference was co-sponsored by Paediatric Haematology and Oncology Society of Bangladesh, Bangladesh Paediatric Association, Association of Paediatric Surgeons of Bangladesh, ASHIC Foundation of Childhood Cancer, Mosabbir Cancer Care Center. The central theme of the conference was "Childhood Cancer is Curable, Lets build on our past". I would like to acknowledge the tremendous efforts of the national and the local organizing committee of 3rd SIOP-Asia Conference especially Dr. M.A. Mannan Chairperson and Dr. Safiq ul Islam - Organizing Secretary.

#### **Scientific Programme**

The scientific programme consisted of symposia, guest lectures, free paper and poster sessions. The topics covered included:

ALL, Retinoblastoma, Lymphomas, Wilm's Tumor, Neuroblastoma, Supportive care, Epidemiology of Childhood Cancer, Hepatitis-B in Pediatric Oncology, Newer Concepts in Radiotherapy, Stem Cell Transplantation in Children, Nutrition support, Late effects, End of life management, Thrombocytopenia and Thalassemia Control Programme. One open panel discussion was held on - "Pediatric oncology experiences from various Asian countries". This panel discussion generated a good response from the audience with the active participation of members from various Asian countries.

#### **Free Papers and Poster Papers**

The 3rd SIOP Asia conference attracted a total of 65 abstracts. Of these, about 50 were selected for oral presentation by the scientific committee and 15 were allowed as posters. papers were received from the countries of Asia and other continents as well (USA, UK, Australia and Egypt). The remaining abstracts were from Bangladesh. All the abstracts have been published in the supplement of 'Bangladesh Pediatric Journal an indexed journal (ISSN): special supplement, abstracts, 3rd SIOP Asia Conference, Vol. 69 (SS No.2): S1-S34. All the abstracts and presentations and posters were of high quality and can be referenced from the above journal. The response was indeed remarkable. Three oral presentations and two ➤

poster papers received the Best Paper Awards

Best Oral Papers :

- RK Marwaha, **D. Bansal**, A. Trehan, N. Verma.  
"Chronic Myeloid Leukemia in Children: Experience of a Tertiary Care Center from North India".
- SM Ahn, KC Park, CD Sun, JT Oh, **SH Choi**, EH Whang.  
"A Clinical Practice of Wilms' Tumor "
- **KS Anwar**, N. Rahman, A. Haque, Faroque.  
"Retinoblastoma in Bangladesh: An analysis of 20 cases in a Tertiary level Eye Hospital".

Best Poster Papers :

- **N Choudhury**, C Bhuyamn, BJ Saikia. "Retinoblastoma in North East Region in India: A retrospective Analysis of 5 years data.
- **MB Hossain**, MJ Rahman, SK Amin, WA Khan, M Selimuzzaman. "Pharmacological treatment of Beta Thalassemia Major & HB-E-Beta Thalassemia Hydroxyurea.
- **S. Khatoon**, MA Mannan, MR Khan, NA Bhau.  
"Fever in Malignant Diseases of Childhood: A Clinicopathological Study.

### Media Exposure: Round Table on Role of society in Management of Childhood Cancer"

A round table on the "Role of society in the management of childhood cancer" was organized by the local team during the conference with the involvement of the international and local experts, representatives from the media, government officials, volunteers from parent organizations and other stake holders. This meeting hopefully will pave the way for coordinating and optimizing efforts towards improving survival amongst children with cancer in this region of Asia. This was followed by a one to one discussion with the President of Bangladesh. Prof. Mannan has taken responsibility to bring out a white paper called "Dhaka Declaration" to emphasize the problems and the action needed to address the issue of childhood cancer.

### Faculty Registrations and Scholarships

About 400 registrations (300 from Bangladesh and 100 from other Countries) were made for the conference including the invited faculty & chairpersons. Of these, about 113 postgraduates in training, junior colleagues and nurses were granted scholarships of variable extent with provisions for free registrations and / or accommodations. Participation from about 20 countries was the highlight of the meeting. From amongst the Asian countries apart from Bangladesh, there were representatives from India, China, Japan, Saudi Arabia, Oman, Singapore, Korea, Nepal and Iran. Certificates of participation were distributed to all the registered delegates. The credit for the success of this conference was due to the wide participation of faculty members not only from India and

Asia but from all over the world. These faculty members from abroad significantly contributed to the success of the programme - Prof. Raul Ribiero, Prof. Sverre O Lie, Prof. Kathy Pirtchard Jones, Prof Hans Peter Wagner. Besides them many faculty members from Asia and Bangladesh also made significant contributions.

### Inaugural and cultural events

The organizing team was influential to have many dignitaries for the inauguration of the conference and therefore create a significant media coverage and hype of the event. The emphasis was to spread the message that 'Childhood Cancer is Curable'. The Honorable Health Minister Dr. Khandaker Mosharraf Hossain was present as the chief guest. He very aptly emphasized the theme of the conference. The other important guests who presided over the inaugural event were Prof. AZM Zahid Hossain, Secretary General, Bangladesh Medical association and Prof. Ma Hadi, President Bangladesh Medical Association and Vice Chancellor, BSMMU. The presence of these dignitaries at the conference would certainly provide a boost to the Bangladesh activities in the field of pediatric oncology. A cultural followed by banquet was organized at the National Museum on Friday 27th February 2004.

### Publications of the conference

In addition to the abstract book as mentioned above, a souvenir "Memorabilia" to record the conference proceedings was also published and released at the inaugural programme. This publication of about 100 pages consists of various articles from all the guest speakers. Copies of the souvenir can be obtained from the organizing chairman Prof. MA Mannan, Department of Pediatrics & Pro Vice Chancellor Bangabandhu Sheikh, Mujib Medical University, Shahbaug, Dhaka-1000, Bangladesh (E-mail: paed@bangla.net / mahmood@agni.com )

### 4th SIOP ASIA CONFERENCE: 2006

4th SIOP-Asia Conference at Shanghai, China in 2006. To obtain further information about this meeting you can reach **Prof. Wang Yao-Ping**, Chairman, Organizing Committee, Dept. of Pediatric Hematology-Oncology, Shanghai Children's Medical Center, Shanghai, China, Telephone: +86-021-58732020, Fax: +86-021-58393915, Email: SCMCmud@online.sh.cn or ypwangscmc@online.sh.cn Suggestions from members regarding topics, faculty, arrangements, and registrations are invited. You may either write to Prof. Yao Ping Wang or to me (parul@bom5.vsnl.net.in). Let us try to make this event also as successful as our previous three SIOP Asia conferences.

### 5th SIOP ASIA CONFERENCE in 2008

The 5th SIOP Asia conference will be held in the year 2008 at Muscat, Oman. The contact details of the concerned persons are **Prof. Zakia Al Lamki or Prof. Mathew Zachariah**, Associate Professor & Head, Child Health Department, Sultan Qaboos University, College of Medicine, P.O. Box 35, Al-Khod, Sultanate of Oman, Postal Code 123, ➤

Telex: 5602 SQU ON Cable: Jami'ah, Telephone: +968-51537,  
Telefax: +968-513419 or +968-515136  
Email: zakiya@squ.edu.om or mathewz@omantel.net.om

## SIOP-ASIA NEWSLETTER

The first issue of **SIOP-ASIA NEWS** is being published regularly! If you have not received a copy, please write to the editor - Dr. M.R. Lokeshwar (Editor-SIOP-ASIA NEWS, email : mrl123@roltanet.com ). It has been very well appreciated by the SIOP Board and the members of SIOP Asia. To popularize this publication, we would like to have your suggestions, inputs, and criticisms. Articles, reports, announcements and other information from members are invited for inclusion in the third publication due before the SIOP Congress at Oslo, Norway. We need your utmost support to promote the success of this initiative. Let this be your mouthpiece and communication link with SIOP Asia.

## SIOP ASIA GENERAL ASSEMBLY 2004

We had occasion to meet at SIOP Asia general assembly in February 2004 at Dhaka. The meeting was well attended and a lot of ideas for future initiatives have been discussed by the members. The minutes of the meetings are attached. The next meeting will be held on Friday 17 September 2004 from 12:30 hrs pm at Vika Sal 3, Oslo Concert Hall, Oslo, Norway. The agenda for this meeting will be as follows:

**Date: 17th September 2004, Friday**  
**Time: 12.30 noon**  
**Venue: Vika Sal 3, Oslo concert Hall, Oslo, Norway.**

1. Apologies and condolences.
2. Confirmation of minutes of meeting held on 27th February 2004, Dhaka, Bangladesh.
3. Business arising out of the minutes.
4. President's report for the year 2004: **Agarwal BR.**
5. Report of the Honorary General Secretary: **Dalvi RB.**
6. Report from Hon.Editor,SIOP Asia Newsletter "SIOPASIA NEWS": **Lokeshwar MR.**
7. 3rd SIOP-Asia Conference 2004 at Dhaka, Bangladesh: **Mannan MA.**
8. Installation of the new SIOP Asia President 2004-2007, handing over charge, election of office bearers for 2004-2007.
9. 4th SIOP Asia Conference 2006 : Shanghai, China, **Prof. Wang Yao Ping.**
10. Report of SAARC coordinator: **Kurkure PA.**
11. Proposals for SIOP-Asia activities: Recommendations and suggestions.
12. Correspondence if any.
13. Any other business with permission of chair.

## DATABASE OF PROFESSIONALS

We are collecting the names and contact details of all professionals serving children with cancer in the Asian continent. Even if they are not members of SIOP, we would like to reach out to them and compliment their efforts in pediatric oncology.

Towards this end we are collecting all information of such personnel. I request you to send me the details of national organizations, their office bearers, members address list especially with emails who are active in the field of pediatric hematology-oncology. This will enable us to build and consolidate a good database of information that would be readily available and useful to our members.

## Acknowledgements

I will be completing three years as President of SIOP Asia at the SIOP Congress in Oslo. During this tenure we have tried as a team to initiate a number of programs and activities and make progress in this region. A lot more needs to be done. I welcome the new SIOP Asia President (There is a contest for the post and you will soon receive the ballot for making the choice. Dr. Purna Kurkure from India and Dr. Wang Yao Ping from China are vying for the post ! ). I wish to place on record the tremendous support received from the SIOP Board and the SIOP Asia Executive committee members to all my endeavors in the past 3 years. I welcome all suggestions from members of SIOP Asia (and others) to augment the programmes and activities of SIOP Asia. The objective is to reach out to more in the coming years. I earnestly appeal to all SIOP Asia members to come forward and strengthen the activities and programmes of SIOP Asia, and contribute to the common goal of achieving cure for all children with the cancer in our part of the world.

## MINUTES OF GENERAL BODY MEETING OF SIOP ASIA 2004

The SIOP Asia General Assembly in the year 2004 was held on Saturday 27 February 2004 at Dhaka, Bangladesh after the close of the 3rd SIOP Asia conference.

There were 27 attendees including the following:

Dr G Choudhary (Bangladesh), DrA Borker(India),  
Dr Damayanthi Pieris(Srilanka), Dr MA Karim,(Bangladesh),  
Dr MS Ashraf(Pakistan), Dr AAH PourFeizi(Iran),  
Dr SH Wasifuddin(Oman), Dr WA Abdullah(Malaysia),  
Dr S Agarwala India), Dr SH Choi(Korea),  
Dr Kailash Sah(Nepal), Dr M Atiar Rehman(Bangladesh),  
Dr ATM Atikar Rehman(Bangladesh), Dr RK Marwaha(India),  
Dr A Sachdeva(India), DrDR MS Khaled(Bangladesh),  
Dr J Scott, Dr M Chaphekar, Dr D Bansal, DR D Ghosh,  
Dr A Mukhopadhyay(India), DrY Tsuchida(Japan),  
Dr Wang(China), Dr Mannan(Bangladesh), Dr B Agarwal &  
Dr R Dalvi(India)

1. **Confirmation of minutes of meeting held at Cairo, Egypt October 2003:** Acceptance of the minutes was proposed by Dr A Sachdeva & seconded by Dr Tsuchida.
2. **Business arising out of the minutes:** Dr Abdullah queried the non-publication of further issues of PHO Newsletter to which Dr BA replied that the editor already had material for publication, but was having difficulty in getting finances for publishing. On the issue of financial ►

considerations, Dr AS stressed that 25% of the registration money of the SIOP Asia meeting should be duly handed over to the SIOP Secretariat as has already been decided at the previous SIOP GBMs. Dr BA reiterated that the SIOP board has earmarked funds for continental programmes to an amount of USD 5000 every 2 years. He added that they had agreed to allocate USD 4000 for the SIOP Asia biannual meeting & USD 1000 for running SIOP Asia. Thus Dr Mannan had received the said amount from SIOP in addition to a generous contribution from Dr Tsuchida. Dr S Ashraf suggested that the annual report should include a balance sheet, to which Dr BA said that the present balance sheet of SIOP Asia was blank, as apart from the seed money reqd for opening a bank account, there was nothing to show with the money from SIOP Asia 2002 was yet awaited. Dr Mannan suggested exploring the possibility of WHO allocation of funds, that he had spoken to WHO officials in Dhaka & suggested that such a proposal could be put up formally.

3. **President's report for the year 2003:**  
Agarwal BR. (as reported above)
4. **Report of the Honorary General Secretary:**  
Dr R Dalvi.  
Dr. Dalvi formally congratulated Dr Mannan & his dedicated team for the conduct of a fruitful scientific meeting with a record attendance & appreciated the hospitality & local arrangements. Dr RD proposed that since SIOP Asia has begun to mature, having been active since 1997, & already three conferences old (with a line-up of 2 more!) ( and going by the more prolific minutes I have to type with each successive GBM!!), it was perhaps time to formally set up certain guidelines for meeting organizers. Dr AS endorsed the same adding that guidelines for scientific programme (as previously decided), should require that 1/3 of the faculty is from the host country (when such is available), 1/3 from Asia & 1/3 from the west. It was decided that a SIOP Asia subcommittee be formed chaired by Dr Dalvi with members consisting of Dr BA (ex-officio), Dr V Rajlingam, Dr Mannan, Dr Arya, Dr Wang & Dr Lamky Zachariah (as suggested by Dr Wasifuddin). This committee would draw out guidelines for holding SIOP Asia meetings & circulate it to the SIOP Asia committee for ratification. Dr Dalvi called for inputs from the SIOP Asia committee members & all SIOP Asia members for the same (could be emailed at rdpho@hotmail.com or bharatdalvi@hotmail.com ). Dr Mannan suggested that we should develop a constitution for the organization. Dr BA said that the post of SIOP Asia president was up for renewal & that there may be 2 interested individuals for the same.
5. **Report from Hon Editor, SIOP Asia Newsletter:**  
Lokeshwar MR.  
Dr MRL sent regrets for his absence & sent a call for contributions for the newsletter, especially re: experiences

from different countries in Asia. Dr Adullah suggested that we use cheaper paper to bring down the cost of publication

6. **3rd SIOP-Asia Conference 2004 at Dhaka, Bangladesh:**  
Mannan MA.  
Dr Mannan placed on record his appreciation of the help provided by SIOP, SIOP Asia President & Committee for organizing the Dhaka meeting. He explained a few of his organizational challenges & how he handled them. He had a total attendance of 375 delegates, including 69 foreign participants (19 scholarships) and 306 local participants (94 scholarships). The scholarship comprised a registration waiver, accommodation, food & local transport. He had given more local scholarships to increase awareness & interest. Regarding the prolonged inauguration he said that in 3rd world countries one had to give importance to politicians to further the cause of pediatric oncology. Dr Abdullah said that it was a job done well.
7. **4th SIOP Asia Conference 2006: Shanghai, China, Prof. Wang Yao Ping.**  
Dr Wang confirmed the dates of the China meeting as April 2006 & that preparations were under way for the same. In response to a suggestion to lower registration fees, he agreed to try to do so after consultation with his local colleagues, in China. The fees would be USD125 before May2005 & USD 250 after that. Dr Wasifuddin suggested that the early registration deadline be forwarded to November 2005 instead of May'05. More oncologists in training could be encouraged by having reduced fees for PG trainees or by scholarships. Dr Wang said that he would try cost cutting measures like holding the meeting in his hospital auditorium instead of a 5 star venue, if the latter was feasible in terms of distance from hotels etc. Dr Choi suggested that we establish electronic submission of abstracts & registration process for ease of communications. Dr Wasifuddin felt 8 mins too short a time to present a research paper, however it was pointed out that this was the standard duration for paper presentation. Dr W also suggested that to save time, introduction of chairpersons could be flashed on the screen & also that the inauguration should be an abbreviated one. Dr RK Marwaha pointed out that we should avoid accepting non-oncological papers for presentation. Dr Agarwala pointed out the need for a more active poster discussion with greater time allotted for interaction. Dr D Bansal suggested that case reports should not be taken for oral presentation & that we should dispense with having a rapporteur to save time.
8. **Report of SAARC coordinator:**  
Kurkure PA.  
Dr BA read out a faxed letter from Dr Kurkure expressing regrets at her absence, adding a proposal to expanding the Indian national training project in Practical Pediatric Oncology to neighbouring countries beginning with a ►

workshop in Nepal in April 2004. She could be contacted at [kurkurepa@tmcmail.org](mailto:kurkurepa@tmcmail.org) for the same.

9. **Proposals for SIOP-Asia activities:**

Recommendations and suggestions.

Dr Mannan said that we should outline guidelines for developing countries to improve Pediatric Oncology facilities & personnel. SIOP Asia should collectively draft a common proposal to submit to their respective governments. Dr Dalvi pointed out that Asia being a continent of widely contrasting socioeconomic strengths, groups of countries from already defined regions within Asia could come together as a regional network, define their unique needs & draft a suitable proposal for those particular regions (eg Middle East, South Asia, South East Asia, Far East etc), rather than a common proposal. Dr Mannan differed & felt that all countries had the same problems. Dr Wasifuddin concurred with Dr Dalvi, but suggested that SIOP Asia could draft a basic proposal & then adapt it to various countries. Dr Mannan was given the responsibility of drafting out the said document & submitting it to the body for approval. Dr Choi suggested that the SIOP Asia presentations could be published as a full paper in the SIOP journal in a supplemental dedicated issue. Dr Bansal suggested that the main SIOP should be approached to fund training in pediatric oncology. Dr BA said that might be difficult & that SIOP is already providing travelling scholarships for SIOP meetings. Dr Kailash opined that, SIOP Asia should be inaugurated by cured patients as a form of encouragement. He also felt that SIOP Asia should address the issue of cost & availability of drugs at a wider level & meetings should also include nurses & nurses' training.

10. **Any other business with permission of chair.**

The meeting was thus concluded with an invitation to meet during SIOP 2004 at Oslo.

**Future SIOP Asia Conferences**

**2006**

**Prof. Wang Yao-Ping**

Chairman, Organizing Committee

**4th SIOP-Asia Conference**

Dept. of Pediatric Hematology-Oncology

Shanghai Children's Medical Center

Shanghai, China

Telephone: +86-021-58732020

Fax: +86-021-58393915

Email: [SCMCmud@online.sh.cn](mailto:SCMCmud@online.sh.cn)

**2008**

**Prof. Zakia Al Lamki or Prof. Mathew Zachariah**

**5th SIOP-Asia Conference**

Associate Professor & Head, Child Health Department, Sultan

Qaboos University, College of Medicine, P.O. Box 35,

Al-Khod, Sultanate of Oman, Postal Code 123,

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[mathewz@omantel.net.om](mailto:mathewz@omantel.net.om)

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## **BANGLADESH - U.K. TWINNING PROGRAMME**

For the week leading up to the SIOP Asia meeting in February 2004, a party from the U.K including Louise Soanes (senior nurse), Tasneem Khalid (principal pharmacist), Kathy Pritchard Jones and Tim Eden (oncologists), Jill and Geoff Thaxter (parents representing ICCCP) visited the centres delivering care for children and the ASHIC Shelter in Dhaka by kind invitation of their Bangladeshi colleagues. They were able at first hand to explore the strengths and needs of each unit. Now they have drawn up a series of recommendations and plans by which they feel further progress can be made to develop paediatric oncology in Bangladesh. They hope that by working with the centres, the local parent organisations, with local politicians ►





Little patients and their mothers at the new paediatric oncology ward of the Bangabandhu Sheikh Mujib Medical University in Dhaka, Bangladesh.

and a range of International bodies including the WHO, the major problems of inconsistent and expensive cytotoxic supply, lack of care treatment plans and supportive care and lack of specific training programmes of nurses and doctors can be overcome.

An amazing amount has been achieved over the last two decades by the commitment and enthusiasm of a few colleagues, which was evident from the excellent organisation of the SIOPI Asia meeting. The U.K. group from London and Manchester feel that a successful twinning programme can now really make a difference.

**Tim Eden**  
President-Elect SIOPI

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## News from the Nurses Group

With a successful meeting in Cairo behind us we look forward to many nurses joining us in Oslo. Before we introduce you to our meeting in Oslo, we want to offer feedback to nurses on the business meeting held in Cairo in order to continue the dialogue regarding the ongoing work of the SIOPI nurses group.

We discussed a number of issues surrounding nurse membership of SIOPI and the benefits that this affords. At the last count we had 43 nurse members. Remember that the membership fee is reduced for nurses and costs Euro 45. Forms are available from the secretariat. And please note that membership criteria are different for nurses' as they only need to attend one meeting to become a member. So what do you get for that? At the moment you would receive this newsletter. We are in dialogue with SIOPI secretariat about increasing our page allowance so that we can provide more information about activities to nurse members and other nurses working within our field. We are also looking into ways that medical SIOPI members can distribute the newsletter to nurses within their departments. We hope to have more information on both of these issues to share at our business meeting in Oslo (see agenda below). In addition, we are in the process of negotiating a reduced rate for the European Journal of Oncology Nursing for nurse members.

We also spent some time discussing mechanisms of communication and forming links between countries. One of the ways we want to improve communication is to develop a database of nurses for each country, through nurses attending SIOPI agreeing to be a link into their local network. Names have been collated from SIOPI 2002 and 2003, and will be

continued in Oslo. We are in the process of identifying access to the data base, maybe through SIOPI web page: again we hope to have more details of this soon.

We were able to present the main components of an addendum to the SIOPI constitution, which had been submitted and we are now able to tell you that the SIOPI board has accepted it. The important feature of this addendum is that we will be able to increase the nurses group, from three non-voted members to 5 voted members. There will be an interim period before all members can be voted on in order to allow for some consistency. The committee will eventually consist of a Chair, past Chair, Chair elect, the Nurses Group representative on the SIOPI scientific committee and one other member. All candidates for election shall be members of SIOPI Nurses Group. We hope to have more news regarding this exciting development in Oslo and will be printed in the next newsletter.

We also discussed the potential for the SIOPI nurses group to undertake activities outside of the annual conference. We discussed a number of options but recognized that we need to increase SIOPI nurses group before we can confidently undertake any further work. One suggestion that may possibly be taken forward was in relation to education and finding out what is on offer in the various countries, whether the EONS Core Curriculum is in use, and what was felt to be needed: this would need to lead on to other activities regarding provision of education. At some point it may be appropriate to co-opt SIOPI nurse members to further this type of work. ➤

Our aim is to continue this dialogue at the business meeting to be held in Oslo Friday 17th September 14.00-15.30. Agenda items for discussion:

1. Introduce SIOP Nurses Group, roles and responsibilities
2. Benefits of membership
3. Communication and web information
4. SIOP member of EONS
5. Database of nursing networks and organisations and their link representatives
6. Annual education programme and future scholarships
7. Cancer Cochrane Group
8. SIOP 2005 Vancouver
9. Any other business

We hope to see many of you at the business meeting, which is open to all nurses attending the meeting. Our three day programme is full and very exciting, with two excellent key note speakers, Roberta Woodgate from Canada and Inger Hallstrom from Sweden. In addition we have two joint sessions titled: supportive care in the community and parents participation

and empowerment. Prior to the conference we are holding an education event for nurses awarded scholarships from the Baltic States: we look forward to reporting on the success of this event in the next newsletter. We would encourage you to look at the web site [www.siop.nl](http://www.siop.nl) for the latest information on SIOP 2004. Of course we would encourage you to register for the event.

Once again can we persuade all doctors who receive this newsletter to share it with the nurses on their unit. If you have any comments or would like more information about becoming a member or about SIOP nurses group then do not hesitate to contact the Chair Faith Gibson, details below.

See you in Oslo.

**Faith Gibson**  
**Lecturer in Children's Nursing Research London UK**  
**Chair of SIOP Nurses Group**  
**Email: [Gibsof@gosh.nhs.uk](mailto:Gibsof@gosh.nhs.uk)**  
**Fax: UK 0207 829 8602**



## Announcements from the secretariat

### SIOP sponsored meetings

We regularly receive requests from SIOP members who organise a meeting, to make use of the name of SIOP or its logo in order to promote their meeting. SIOP is willing to do so, but in order to guarantee good quality meetings carrying the name of SIOP, there are several requirements to be fulfilled by the organisers:

If you are organising a meeting or workshop and you wish to include the name of "SIOP", please note that:

- The faculty of the meeting/workshop has to consist of (partly) SIOP members
- The programme of the meeting/workshop has to be submitted for review to the SIOP Scientific Committee **at a minimum of 6 months before the meeting takes place**

Please note that SIOP will not allocate any financial support to the meeting, just the use of the logo!

This information is also to be published on the SIOP web site.

### Invitation to Members of SIOP Europe

SIOP Members from Europe who would like to host the SIOP annual meeting, are asked to send in a bid for the organisation/hosting of this annual meeting in 2008. Bid information can be obtained at the SIOP Secretariat or on the SIOP web site.

### Bids are to be received at the Secretariat prior to September 1, 2004.

Originally the meeting in Europe was planned for 2009. However due to the

ECCO meeting in 2009, this would provide a significant conflict with the SIOP annual meeting. As a result, and with the consent of the Continental Presidents, the venue for the 2009 SIOP annual meeting has been changed to Africa, Mexico, Central or South America.

### Invitation to Members of SIOP in Africa and in Latin/South America or Mexico

SIOP Members from the above mentioned continents who would like to host the SIOP annual meeting, are asked to send in a bid for the organisation/hosting of this annual meeting in 2009. Bid information can be obtained at the SIOP Secretariat or on the SIOP web site.

### Bids are to be received at the Secretariat prior to September 1, 2005. ➤

Originally the meeting in 2008 was to be held in Africa, Mexico, Central or South America. However the ECCO meeting will be held in 2009 (it occurs every other year). This would provide a significant conflict with the SIOPI annual meeting that was to be held in Europe in 2009. As a result, the venue for the 2008 SIOPI annual meeting has been changed to Europe, and that for the 2009 SIOPI annual meeting to Africa, Mexico, Central or South America. Please notify the SIOPI Board, through the SIOPI Secretariat (secretariat@siopi.nl) of your interest in submitting a bid after consultation with your colleagues and the appropriate SIOPI continental president.

### **Congratulations to the Oslo Schweisguth Prize Winner**

The Schweisguth Prize was won by Ulrika Kreicbergs from Sweden. Her paper was titled: „ Care related stress in parents losing a child to cancer: A population-based long-term follow-up“. She will present her paper at the SIOPI Oslo congress on Saturday, September 18, 2004 from 13.20 to 13.50 hrs. The booklet with her paper will be available at the Oslo meeting and will also be included in the 2004 December newsletter mailing.

### **SIOPI Call for dues - Reminder**

Those members who have not yet paid their fees of 2003 (and former years) , will find with this newsletter a reminder to pay their fees. Please be informed that if you have more than 1 year of outstanding fees, your subscription to PBC will be withdrawn. Back issues will not be sent after late payment. Outstanding fees for 2004, can still be paid till September 1, 2004, or on site at the Oslo congress.

### **Leaving of officers and welcome to new officers SIOPI International**

As mentioned in the former newsletter, we asked you to nominate people for the following positions due to the ending of their terms of office:

#### **Continental Presidents**

Continental President of SIOPI in Africa:

We received a letter by the current Continental President, Prof. Khalek, noting that the African SIOPI members nominated Prof. F. Msefer Alaoui from Morocco as the new Continental President of Africa. Congratulations!

Continental President of SIOPI in Australasia/Oceania:

From the members of this continent we received the request to have Keith Waters stay on for a second term. This was approved and Dr. Waters will remain the Continental president for the coming 3 years.

Continental President of SIOPI in Asia:

At present a ballot is being held between Drs. P.A. Kurkure from India and Dr. Y.P. Wang from China. Good luck to both of you! We will let you know in Oslo who will be the new SIOPI Asia President.

#### **Scientific Committee of SIOPI**

Translational Science

You all received a ballot form to vote for a translational scientist to be on the Scientific Committee. In Oslo you will hear who the winner is!

Epidemiology

The Epidemiologists voted on their group representative themselves and this has become Dr. Andy Olshan. Welcome on the Scientific Committee!

Please find a small introduction by him to you:

CV:  
Andrew F. Olshan, Ph.D. is Professor in the Department of Epidemiology, School of Public Health, University of North Carolina, Chapel Hill. He received his Ph.D. in Epidemiology from the University of Washington. He was a Postdoctoral Fellow in Medical Genetics at the University of British Columbia, Vancouver, Canada from 1987 to 1989 and Assistant Professor in the Department of Clinical Epidemiology and Preventive Medicine, University of Pittsburgh from 1989 to 1991. He has been on the faculty at the University of

North Carolina since 1992.

“For most of my career I have been interested in the epidemiology of childhood cancers including the etiologic role of environmental exposures and gene-environment interactions. In pursuit of this goal I have directed several large North American epidemiologic studies of risk factors for childhood cancer including a study of neuroblastoma and two studies of Wilms tumor. These studies were conducted with the Children’s Oncology Group, an experience that has greatly impressed upon me the necessity for cooperative multidisciplinary research to advance our understanding of the causes of childhood cancer. The full collaboration of epidemiologists, clinicians, basic scientists, and others will foster cutting-edge research. As a member of the Children’s Oncology Group Epidemiology Steering Committee, I am hopeful that further exchange and collaboration are possible between North American epidemiologists and those conducting similar research elsewhere. I consider my participation as a member of the SIOPI Scientific Committee as a unique opportunity to promote such international collaboration.”

#### **Board of SIOPI**

Treasurer

In a mailing earlier this year we asked you to nominate people for the position of treasurer. We also noted that Prof. Anjo Veerman from the Netherlands, who is the current treasurer, was willing to stand again.

We received nominations that supported his continuation of this position, and we received a nomination for Dr. Max Coppes from Canada. Please find therefore a ballot together with the newsletter for you to vote between these two nominees.

Ballot papers have to be back at the secretariat by September 1, 2004. Good luck to both candidates!

#### **Sponsoring a member from an OECD developing country for Euro 75.-**

You can sponsor a SIOPI member of a PODC country by adding to your ➤

membership fees the amount of Euro 75.-. The PODC Committee together with the secretariat will select the members who are eligible for this sponsorship.

**Duplicate issues of "Medical Pediatric Oncology (MPO)" (to be "Pediatric Blood and Cancer" (PBC))**

If you receive at your hospital duplicate issues of MPO/PBC, which are not used by you or your colleagues, you can have the duplicate issue sent to a paediatric oncology colleague in a less affluent country for whom MPO could be very

helpful. This suggestion was already made some years ago by Dr. D'Angio and we keep on repeating this. In case you have an additional issue and you wish to have it sent to somebody else, please contact the secretariat. The secretariat will then check with the PODC Committee chairman where to send this.

**Free access to medical journals**

Free access to over 1.000 of the world's leading medical journals, including MPO, for those in developing countries. Information can be found on:

[www.healthinternetwork.net](http://www.healthinternetwork.net)

**SIOP Web site**

Please be reminded that the SIOP web site can be found at [www.siop.nl](http://www.siop.nl). You have received a password and personal username and should be able to visit the "Members only" parts.

If you have any problems entering these parts or otherwise, please contact the secretariat. We would like everybody to be able to visit the site without difficulties. Also, if you have any suggestions or comments on the site, please contact the secretariat: we need your input! ■



## **Minutes, XXXIII SIOP CONGRESS, CAIRO, EGYPT ANNUAL GENERAL ASSEMBLY**

**Thursday, October 9, 2003 from 18.00-19.00hrs**

**1. Opening**

AC opens the meeting and welcomes all members present.

**2. Minutes of the XXXIV Annual General Assembly, Porto, Portugal**

September 19, 2002

Amendments to minutes

AC asks if anyone has any corrections or comments on items in the minutes.

No comments or corrections are made and the minutes are approved as a correct record.

**3. Report from the President**

Moment of silence for deceased SIOP members

Developments re. SIOP (PODC/other)

AC asks the assembly for a moment

of silence for three deceased SIOP

members: Drs. M. Tefft,

J. Boguslawska-Jaworska and J. Kuhl.

- SIOP 2002, Porto Portugal: AC notes that the 2002 congress was looked at by many as the congress where everybody had to go on the long bus drive, however, due to these

transfers, people became well into contact with each other and many new friends between participants were made. The 2002 congress had good science, and all sessions were well attended.

- SIOP 2003 Cairo: During the first days, many people complained more or less on the high registration fees, but later more and more compliments were made on the contents of the 2003 meeting. Again, the meeting appears to become a success.

- Meeting costs: The high registration fees are due to the large meeting costs. SIOP are trying to reduce these costs every year, but the organisation of an international meeting with over 1,000 participants is quite complex and costs a lot of money.

MPO will become PBC: The journal "Medical Pediatric Oncology (MPO)" will become "Pediatric Blood and Cancer (PBC)" as of January 1, 2004. Reason behind this is that ASPH/O had requested SIOP if they could have a joint journal with SIOP. After deliberation by the Board, this was

agreed and PBC will become the official journal of SIOP, ASPH/O, IPSO and the Histiocyte Society. JPH/O will keep on existing, but ASPH/O will no longer consider this as their official journal.

The new Editor-in-Chief of PBC will be Dr. R. Arceci. Dr. G. D'Angio is thanked for his contribution as Editor-in-Chief. He receives a present by the Board. All members give Dr. D'Angio an applause and a standing ovation.

**4. Report from the Treasurer**

New members/Honorary members/Resignations/Membership dues/Accounts/Budget 2004

AV presents the treasurers report:

He notes on the income minus expenses: Income was Euro 179,220, Expenses were Euro 180.028: the result is Euro 808-

AV notes that there are still 517 members who have outstanding fees. The amount of these outstanding fees from 1998 till 2003 is Euro 133.332. The budget proposal for the year ▶

2003-2004 will be that income and expenses will be Euro 213.000. See enclosed overview in this newsletter.

AV notes that in this proposal the costs of 1 extra person working for the secretariat part time is included. This has been decided upon because the secretariat will become more active in the organisation of the future congresses of SIOP.

AV summarises the financial situation of SIOP:

Deficit budget 2000-200:	16,165 (was in US\$)
Deficit budget 2001-2002:	41,439
Deficit budget 2002-2003:	808
Projected deficit 2003-2004:	15,000
Capital (minus 808)	84,230
Continuity fund (minus 2,394)	266,989
(Target continuity fund	400,000)

AV notes that taken into account the inflation percentage of 4% per year and the fact that the fees have not been raised during the last year, he proposes a slight raise of the membership fees.

Proposal fees 2003-2004:

Ordinary member:	Euro 225
Ordinary member PODC:	Euro 75
Member in training:	Euro 75
Associate member:	Euro 60
Nurse member:	Euro 50
Fellow:	free
Honorary member:	free

New members/Honorary members/Resignations

The following members became Honorary members:

J.M. Zucker, C. Bailey, J. Hoogenhout, G. Lundell, M. Radford

Two (2) members resigned from membership

Three members deceased: J. Kühl, J. Boguslawska-Jaworska and M. Tefft  
Eighty-three people applied for

AC asks if the members have any questions regarding the treasurers report.

J. Wolff notes that he would like to see more transparency in the congress budget. AV notes that he can understand this question and he proposes to show a condensed version of the budget in the newsletter. AV adds that the Board will do their best to reduce the meeting costs, but this

depends on many factors. Having the SIOP secretariat more involved in the meeting organisation has also been done in this respect.

H. Caron asks what the projected congress income is. AV notes that in the past two years this was close to zero or negative. H. Caron notes that there should be more information provided before deciding on a venue. AC notes that this has now been in the proposal of the amended statutes.

G. Henze notes that most costs are in US\$. The euro is stronger than the \$, so why should the fees be raised? AV replies that only the subscription to the journal is paid in US\$. The rest of the costs of SIOP are in Euros.

AC asks the members if they agree to the proposed budget and increase in membership fees. Everybody agrees to the budget and membership fee increase.

#### 5. Report from the chairman of the Scientific Committee

- Meeting format: KPJ asks feedback from the membership regarding the format of the SIOP meeting. Are they happy with the present format, or do they have other ideas or suggestions. She notes that there will be a change in the format of the Nöllenburg/Fasanelli prize sessions. Due to the difficulty in finding every year an outstanding paper on Bone or Ewings tumors, the Board and Scientific Committee had requested to use the money that is donated for these sessions, to be spent in another manner than before. This was at least agreed upon by the Fasanelli family. Instead of using it as prize money, it can be used as money to organise a symposium or as scholarship money.

- Clinical trials: KPJ asks the members what they feel regarding the role that SIOP should play with regard to clinical trials. Should SIOP continue to endorse trials and run the risk of being liable in any way, or should SIOP no longer act as such. How would this affect trials in the PODC countries?

KPJ would like to receive feedback from the members on this before

January 2004.

- Officer positions vacant: KPJ notes that in 2004, 4 posts will become vacant. A call for nominations will go out in the December newsletter and elections will then be held in the spring of 2004. Positions that become vacant are the post of Epidemiology representative; 2 posts for translational researchers and a post for a more clinical scientist. KPJ notes that working on the SIOP Scientific Committee is quite hard work, but also a lot of fun, so therefore do put yourself forward!

- Use of SIOP logo: The Scientific Committee and Board of SIOP are often asked for the use of the SIOP logo in a meeting on or related to paediatric oncology by SIOP members. The conditions on the use of the logo have been in the newsletter and are on the web site. They are as follows: The meeting contents should be submitted to the Scientific Committee at the earliest stage possible, but at least 6 months before it taking place. The faculty should consist of SIOP members.

G. D'Angio thanks KPJ for her enormous hard work and urges the senior members to put their younger colleagues forward.

I. Lewis notes that the issue of clinical trials is very complex and should be discussed in detail.

6. - Report from the Secretary-General Before dealing with the agenda items listed, DG asks the membership if they agree to the membership of the 83 applicants. There are no objections and all applications are accepted.

- Leaving of Board member and LOC chair 2003 El Hamy Rifky-Khalek and welcome on the Board Sverre Lie, LOC chair Oslo 2004

DG thanks Prof. Khalek for all his efforts in making this congress a big success. It has been quite a difficult year, but it was worth it. Prof. Khalek is thanked for his hospitality, generosity and hard work on behalf of the Board and the participants.

Prof. S. Lie is welcomed on the Board as the new Chair of the SIOP 2004 Oslo meeting.

- Vote on the revised Constitution proposed in a mailing to the ➤

membership

DG presents the changes proposed and mailed to all members prior to the congress. The amendments are related to the following:

- Clinical Trials: Item IX of the By-Laws accepted in 1999 and 2000, has been removed. This referred to the participation in and assistance to clinical trials.
- Membership categories: A new category was added: Members in Training. This category was added to enable more young trainees to become a SIOP member against a reduced rate.
- Membership requirements: in order to become a member, one had to have attended 2 annual meetings. This is changed and membership can now be realised if one of the meetings has been an annual or SIOP Continental meeting.
- Officers: The term of the Treasurer has been changed into more than one three-year term. This was a single three-year term. This was done to get a better continuity in the society's finances.
- SIOP Council: This will be a new body, consisting of the Board and the Continental Presidents. It is established to discuss and co-ordinate the broad strategy for the SIOP activities worldwide. The Council will play a part in proposing regional members as hosts for the annual meeting and will decide on the choice of the annual meeting venues.
- Scientific Committee: This Committee will have 10 instead of 9 members and there will be a slight amendment in the discipline groups. Instead of representatives of basic science (1) and paediatric oncology (3), the representatives will be from clinical trials (2) and translational research (2). A new group representative will be from Bio-statistics (1).
- Rotation of the annual meeting venue: It will be held in a different continental location each year. This is done in order to increase the number of meetings in PODC countries.
- Result of the annual meetings: A separate foundation will be established to deal with the financial result of the meetings in order to reduce the liability of the Board

members.

AC asks the membership if they have any objections regarding the proposed changes.

Membership categories/membership requirements/:  
No objections

Annual meeting result management/  
Annual meeting venue selection:

Guenter Henze notes that referral is made to the term "SIOP International". This should only be "SIOP". The Board agrees and will change this.

Guenter Henze also objects to the establishment of a separate foundation for the meetings.

H. Caron notes that if an annual meeting has a surplus, SIOP would want to be in control of this surplus, however, if it is a deficit, SIOP would not.

AC explains the policy regarding foundations. If there is no separate foundation that is only involved in the meetings, the Board could be considered as liable. The membership has no other objections and agree to this proposal.

J. Lemerle asks the Board to take into account the costs of travel when selecting a meeting venue. AC answers that the Board and Continental Presidents will do so.

G. D'Angio asks if the continents agree to the rotation as proposed in the by-laws. AC notes that this proposal was known to the Continental Presidents and they agreed to this proposal.

H. Mahmoud inquires on what will happen if there is no continent willing to host a meeting. AC notes that the Council will then decide on where to go.

C. Patte notes that it has to be made sure that there is an even alternation in Europe and North America. This is agreed by the Board.

SIOP Officers/Scientific Committee composition/ Treasurers term:

G. D'Angio notes that when voting for the Scientific Committee, one should take an odd number. This is agreed.

J. Pritchard notes that he does not object to the change of term with

regard to the treasurer's position, but would like to know what the qualifications are for the job. AC notes that this will be defined as soon as the position becomes vacant.

SIOP Council:

M. Coppes asks whom the Council is accountable to. AC notes that the chair of the Council is the SIOP President. The Council further accounts to the SIOP members.

J. Pritchard asks if SIOP can afford the new arrangements made regarding the Scientific Committee and the Council etc. AC replies that this is still calculated within the annual society budget.

Clinical trials:

AC explains that SIOP wants to continue supporting clinical trials, but do not want to be held liable. SIOP needs to be protected and therefore the part regarding clinical trials has been changed.

G. D'Angio notes that the phrase in Article II, item 5, does not belong here. It should only be mentioned what the aim is, not what you do not want to do. He suggests to leave the wording as it was.

It is better to change the by-laws, and not the constitution. AC agrees to Dr. D'Angio's arguments and proposes to keep the original wording.

H. Caron notes that the part under item 5 on the Scientific Committee can be added to the part in the by-laws under Article VIII, 1.A.

## 7. Report from the Editor-in-Chief, MPO, G. D'Angio.

G. D'Angio thanks the Board for the honours and the members for all their help in the past years. He notes that PBC will be an expanded version of MPO. G. D'Angio introduces Arceci, the new Editor of PBC. G. D'Angio wishes him well in his new position.

R. Arceci thanks the Board and G. D'Angio for their help in making the transition to PBC. He notes that he will continue in the line of G. D'Angio, but that some changes will take place.

## 8. XXXVI SIOP Congress: Oslo, Norway, ➤

### September 16-19, 2004

First a short video presentation is held. After this S. Lie welcomes everybody to Oslo. He lists the speakers that have been confirmed for the meeting and informs the membership on the venue, which will be located in the city centre.

### 9. Future congresses

Vancouver, Canada, 2005;

Geneve, Switzerland, 2006

AC notes that the dates for the above-mentioned meetings are as follows:

Vancouver, Canada:

September 21-25, 2005

Geneva, Switzerland:

September 19-23, 2006

### 10. Venue SIOP Annual Congress 2007

New procedures for election of venue.

In 2007 the meeting will be held in Asia. The exact place and dates will be made known in due time. There have been bids received from Hong Kong and India. In 2008, the meeting will be held in Latin America.

### 11. Any other important business

KPJ (Chair of the Scientific

Committee) informs the membership

that Dr. G. Perilongo will be the new chair of the Scientific Committee as of after Oslo, 2004.

KPJ also wishes to thank Prof. Khalek on behalf of the Scientific Committee for his hard work on the Committee with respect to the programme, and to his hospitality in Cairo.

AC asks if there is any other important business. There is no other business and AC closes the meeting at 19.25 hrs. He thanks all members present for their attendance.

### An attendance list was circulated during the Annual General Assembly.

The following 131 members signed the list:

M.V. Abesamis	B. Dembowska-Baginska	V. Koseoglu	R. Riccardi
E.R. Abdel Khalek	C. Dhooge	P.A. Kurkure	B. Sandstedt
L. Agaoglu	F. Doz	M.T. Kutluk	K. Schmiegelow
B. Agarwal	T. Eden	B. Lannering	D.T. Schneider
S. Aksoylar	R.M. Egeler	G. Laureys	R. Severino
C. Akyüz	J. Eguiguren	J. Lemerle	B. Sevinir
A.M. Al-Jassmi	S. Emir	I.J. Lewis	M.M.K. Shing
R. Al-Hayek	A.E. Evans	S.O. Lie	M.C.G. Stevens
G. Al-Harbi	A. Fernandez-Teijeiro	L.R. Lockwood	E. Smibert
D.C. Aronson	D. Frappaz	G.A. Mackinlay	D. Sommelet-Olive
L.S. Arya	A. Glomstein	H.H. Mahmoud	I. Storm-Mathisen
A. Balcerska	A. Gnekow	I. Marky	M.J. Sullivan
W. Balwierz	U. Göbel	H. Martelli	N. Tacyildiz
K. Bartyik	J. Godzinski	R.K. Marwaha	P. Tamaro
C. Bergeron	N. Graf	G. Masera	E. Tugrul Saribeyoglu
F. Berthold	S. Graphakos	A. Meral	F. Tzoztatou-Stathopoulou
C. Bhuyan	D.M. Green	F. Msefer Alaoui	C. van den Bos
J.M. Birch	M.A. Grotzer	J. Michon	S. van Gool
M. Büyükpamukçu	J.L. Habrand	H.L. Müller	A. Varan
G. Calaminus	H. Hassab	A. Navajas	A.J.P. Veerman
C. Calvo	M. Herbst	R. Nygaard	C.R. Vergin
V. Canale	P.B. Hesseling	I. Ora	P. Wacker
H. Caron	L. Hessissen	N. Pal	J. Walker
M. Carli	L. Hovi	C. Patte	D.A. Walker
C. Carrie	I. Ilhan	M. Perek-Polnik	H. Wallace
M. Coppes	H. Irving	A.S. Petrilli	F. Wesenberg
A.W. Craft	M. Jankovic	R. Pinkerton	G. Wessels
A. Dabezies	M. Kaczmarek-Kanold	J.E. Poole	E. Widing
G. D'Angio	G. Kapoor	J. Pritchard	J.E.A. Wolff
R. Dalvi	B. Kazanowska	K. Pritchard-Jones	W. Wozniak
B. de Camargo	R. Kebudi	A. Raciborska	N. Yaris
J. de Kraker	A. Kelsey	Y. Ravindranath	I. Yildiz
C. Devalck	J. Kingston	G. Reaman	



Childhood Liver Tumours  
Strategy Group - SIOPEL

# INTERNATIONAL CHILDHOOD LIVER TUMOUR STRATEGY GROUP - SIOPEL

## Up-date of clinical research activity May 2004

Dear Members,

As most of you know the International Childhood Liver Tumour Strategy Group - SIOPEL - is a group of medical specialists founded in 1988 under the umbrella of the International Society of Paediatric Oncology (SIOP). Its main aim is to promote basic and clinical research on childhood malignant neoplasm of the liver, mainly hepatoblastoma and hepatocellular carcinoma.

The principal missions of the SIOPEL group are:

- To develop comprehensive clinical research programs on childhood hepatoblastoma and hepatocellular carcinoma;
- To promote basic and translation research in this field, making also available biological material derived from these rare patients;
- To promote world-wide cooperation;
- To develop research programs for treating childhood liver tumours in countries with limited economic resources;
- To develop models for running international research on rare tumours.

Structure – Until now the group has not given itself a rigid structure, however at this stage of development the key and operative elements of the SIOPEL group are:

- Group general secretary;
- A strategy group Core Committee
- Clinical Trial co-ordinator/Data manager
- Discipline panels and discipline panel chairman;
- Project leaders;
- Non European continental representatives;
- Biostatistician;
- (UKCCS) Trial Center, Chief Executive,
- Independent data monitoring committees.

The founding elements of the group are:

- The UKCCSG trial office in Leicester UK, directed by Dr. Sue Ablett which functions as the group trial centre providing also the clinical trial co-ordination in the figure of Mrs Margaret Childs and the treasury activity (Dr. Sue Ablett)
- The SIAK which provide, in the figure of Dr. Rudolph Maibach, the biostatistical service
- The CINECA , the non-profit making Italian inter-university organisation which provides the group with the AMR system (Advanced Multicentric Research) a system based on WEB technology for collecting, handling and elaborating data.

Financial support - The activity of the group as a whole has never been funded. The major source of funds to run the studies has so far been:

- Cancer Research UK
- The Swiss Cancer League
- Private donations

### Activities

**The past** - The SIOPEL group has so far completed and fully published two generations of prospective clinical trials and a Phase II study, called

- SIOPEL 1 - 1990/1994
- SIOPEL 2 - 1994/1998
- Phase II study on High dose Cyclophosphamide - 1996/2001

**The present** - Presently the group is running

- A prospective randomised clinical trial on Standard risk hepatoblastoma - SIOPEL3a - Trial main coordinators G. Perilongo (I), E.Shafford (UK), J. Plaschkes (CH), ➤

- L. Brugieres (F), D Aronson (NT) & others
- A prospective single arm trial on high risk hepatoblastoma – SIOPEL 3b - Trial main coordinator G. Perilongo (I), L Brugieres (F), E.Shafford (UK), J Zsiros (NH), JB Otte (B), D. Aronson (NT), P. Czauderna (P) & others
- A Phase II study on Irinotecan - Trial main coordinator J.Zsiros (NH), L. Brugieres (F), P. Brock (UK) & others
- An international tissue bank for childhood liver tumours - M. Grotzer (CH)

#### The future – The group is planning

- A new study on high risk hepatoblastoma; SIOPEL 4 - expected opening time 01/2005 - Trial main coordinators J.Zsiros (NH), P Brock (UK), L. Brugieres (F), JB Otte (B) and others
- A prospective single arm trial on Hepatocellular carcinoma; SIOPEL 5 - expected opening time 06/2005 - Trial main coordinators P. Czauderna (P), B Morland (UK); M. Casanova (I),
- A worldwide registry on Pancreatoblastoma - M. Sullivan (NZ) & P- Dall'Igna (I)
- A prospective single arm trial in cooperation with the Indian Paediatric Oncology Society - SIOPEL 6 expected opening time - 06/2004 J. Pritchard (UK) and Dr.Ram Marwaha ,PHO Chapter of Indian Academy of Pediatrics
- An international network of laboratories dedicated to develop new drugs and running pharmacologic researches in vitro and in animals on childhood HB and HCC Project leaders : B. Morland (UK), L. Brugieres (F)
- The constitution of a working group for elaborating phase II studies on childhood liver malignancies Project leaders : B. Morland (UK), J. Zsiros (NT), L. Brugieres (F), P. Brock (UK)

#### The major immediate challenges

The major immediate challenge that the group wants to face is the completion on the present randomised trial for standard risk HB - comparing Cisplatin (CCDP) alone Vs CDDP/Doxurubicin - recently up-graded to reach the statistical power to make it a "superiority trial". In other words, following the data monitoring committee's recommendations,

the group aims to recruit an amount of patients which will show whether or not the CDDP monotherapy arm is superior or inferior to the standard CDDP/DOXORUBICIN arm. Up to March 2004 406 children with a primary hepatic tumour have been enrolled into the study; 349 were HB; out of this 349 patients, 164 have been randomised. The accrual recruitment goal is 250 patients in total. We have decided to go for it!!

The second major challenge is, starting from the SIOPEL4 trial, to move the data collection system from "paper" to the "Data Remote Entry System" thanks to the co-operation with CINECA, a non-profit making inter-University organisation capable of providing all the resources necessary for running the trial through a WEB based system. The system is almost ready to go. SIOPEL 4 will be open to patient' recruitment as of January 1st 2005. We all are excited about this development which is expected to facilitate the large-scale participation of centres to the trial. Please note in Oslo, at the time of the SIOPEL Annual Conference, a major part of the SIOPEL Committee meeting will be devoted to the presentation of this system.

The third major immediate challenge is to launch an international childhood liver tumour tissue bank (beware: the material is not for consumption!).

#### Next group appointments:

Oslo; SIOPEL Annual Conference September 16-19, 2004 - Open SIOPEL Committee meeting (precise date and venue to be established)

Berne, March 10 and 11, 2005 Bernese workshop on the hepatocellular carcinoma family of tumours and Winter SIOPEL Committee meeting

PLEASE NOTE VERY SOON A NEW SIOPEL WEB PAGE WILL BE OPEN

The SIOPEL Group - Edinburg (UK), March 2004 ►



# THE RIGHT OF CHILDREN TO FULL ACCESS FOR ESSENTIAL TREATMENT

Led by Guiseppe Masera and Ching-Hon Pui, the Ponte di Legno Group of A.L.L. Collaborators from around the world produced and approved a Mission Statement to be submitted to the World Health Organisation and to be published in key medical journals.

This statement was approved and signed by the Board of SIOP at its meeting on Wednesday April 21st 2004 on behalf of the membership as part of our strategy to help the estimated 80% of children in the world who do not currently receive any treatment - not even basic supportive or palliative care. Although initiated for leukaemia it has relevance for all common cancers.

## **Position Paper/Statement by Members of the Ponte di Legno Group on the Right of Children to Have Full Access to Essential Treatment for Acute Lymphoblastic Leukemia**

Improved outcome of childhood acute lymphoblastic leukemia (ALL), the most common cancer in children, is one of the great success stories in modern medicine. The approach taken to dramatically improve the cure rate involved the combination of clinical and basic research, mostly conducted with public funds, and intensive collaboration of cooperative groups. As a result, the cure rate has improved from 3% in the 1960s to 80% currently in resource rich countries. We believe that this improved possibility of survival should be considered a fundamental right of affected children. Providing access to the necessary diagnostic and therapeutic resources for children afflicted with leukemia should be a priority for those who play a role in the relevant areas of medicine and health. The physicians, clinical investigators, and basic scientists who have signed this statement have been responsible for transforming ALL into a model disease for which there is hope of cure when optimal treatment is accessible. These professionals are fully aware that their successes have also widened the gap of inequality between children living in the resource-rich countries and those living

in low-income countries (LICs). Most children live in LICs; hence, most patients with ALL reside in these countries and therefore are subjected to an increased risk of possibly avoidable death.

As citizens, doctors, and researchers, we feel an urgent priority to correct this inequality in ALL treatment. The following is a summary of short- and medium-term plans in this regard:

- 1 The first and most rapidly achievable goal is the recognition by international agencies and by concerned regulatory authorities that the treatment protocols and guidelines developed for children with ALL are essential. In this regard, antileukemic drugs used in these protocols should be qualified as "essential" drugs.
- 2 Centers or groups of excellence should be developed in LICs. Our experience in various LICs has shown that the efficacy and safety of chemotherapy can be ensured in centers and by groups who are trained and motivated to adopt policies of high-quality ALL care, which include the use of well-designed protocols.
- 3 On the basis of concepts and strategies developed for use in other disease areas (from tuberculosis to AIDS), we recommend broadening the scope of the "essential drugs list" and documenting not only the selection and use of drugs but also the implementation of the treatment strategy.
- 4 Within a framework in which the fundamental rights of children are the reference value, we commit our groups to strongly support all activities toward this goal; but we request the recognition by WHO and other concerned national and international agencies that the care of children with ALL as well as other curable cancers) is deemed essential.
- 5 We advocate a price policy for drugs used in the protocols; the purpose of the policy will be to diminish substantially the treatment barrier of high drug costs; we recommend that the national authorities support the centers where the staff are committed to "essential

protocols" and that national authorities document compliance with these protocols.

We are only too aware that the resource allocation for ALL does not currently coincide with public health priority in many countries. However, we are convinced - and supported by our experience - that ALL is a model for all curable cancers; expanding efforts in treatment of ALL in LICs will result in the mobilization of important new energies, stimulation of imaginative solutions, enrichment of motivations, and broadening of public awareness. We emphasize that a policy of drastic cost-cutting in ALL treatment is feasible for two main reasons (besides and beyond any ethical consideration):

1. the market implications are minimal, because the size of the patient population is relatively small; and
2. there will be no risk of misdirection or mismanagement of drugs as they become available, because their use will be accounted for by centers of expertise who are committed to documenting compliance through registration of all patients enrolled on treatment protocols.

All subscribers to this memorandum, representing the majority of the Childhood Leukemia Treatment Consortia, herewith emphasize the right of all children in the world to full access to the essential treatment of ALL and other cancers, and call upon all authorities concerned to recognize and support all measures that can promote this right to a "chance of cure".

Reprinted with permission, from Pui et al. Leukaemia, in press.

## **This statement was approved in principle by the following representatives of these study groups in San Diego December 2003**

- Associazione Italiana di Ematologia ed Oncologia Pediatrica (AIEOP):  
M Arico, G Basso, A Biondi, V Conter, G Masera, G Tognoni, MG Valsecchi
- Berlin-Frankfurt-Münster Group (BFM):  
G Cario, H Gadner, O Haas, J ➤

- Harbott, R Panzer, H Riehm, M Schrappe, A Stackelberg, M Stanulla, M Zimmermann
- Children's Oncology Group (COG): B Camitta, W Carroll, P Gaynon, S Hunger, J Nachman, K Schultz, N Winick
  - Cooperative Study Group for Childhood Acute Lymphoblastic Leukemia (COALL): M Horstmann, G Janka-Schaub
  - Czech Pediatric Hematology (CPH): J Sary, J Trka
  - Dana-Farber Cancer Institute (DFCI) ALL Consortium: S Sallan, L Silverman
  - Dutch Childhood Oncology Group (DCOG): R Pieters, A Veerman
  - European Organization for Research and Treatment of Cancer-Childhood Leukemia Group (EORTC-CLG): Y Bertrand, S Suciu
  - French Acute Lymphoblastic Leukemia Study Group (FRALLE): G Leverger
  - Japan Association of Childhood Leukemia Study (JACLS): K Horibe
  - NCRI/Medical Research Council Childhood Working Party, United Kingdom Acute Lymphoblastic Leukemia (MRC-UKALL): T.O.B Eden, C Harrison, B Gibson
  - Nordic Society of Pediatric Haematology and Oncology (NOPHO): E Forestier, K Schmiegelow, K Vetteranta
  - St. Jude Children's Research Hospital (SJCRH): D Campana, E Couston-Smith, WE Evans, R Handgretinger, C-H Pui, MV Relling
  - Taiwan Pediatric Oncology Group (TPOG): D-C Lang
  - Tokyo Children's Cancer Study Group (TCCSG): A Manabe, M Tsuchida
  - D Pinkel
  - International Society of Paediatric Oncology: A Craft, T.O.B Eden, A Veerman, D Green, K Prichard-Jones, S Lie on behalf of the members of SIOP

# Impressions from ASPO Postgraduate Course in Paediatric Oncology

## *"From gene to cure"*

**Amsterdam School of Paediatric Oncology  
12-16 January 2004**

I attended the Postgraduate Course 2004 which was held from January 12th to 16th by Amsterdam School of Oncology (ASPO) at the Academic Medical Center (AMC) of University of Amsterdam. This was the first time that I had been to Amsterdam. Although cloudy and rainy most of the time, the weather was nice compared to freezing cold in Ankara on the same days. Amsterdam is a very beautiful city with its well preserved historical buildings, beautiful streets and canals, and most of all its friendly people.

The scientific program of the ASPO Postgraduate Course on Paediatric Oncology was well organised and busy one, the scope of which was properly reflected by its title 'from gene to cure'. The venue for the course was very appropriate since AMC is a big referral and research center which made us feel very enthusiastic to attend all the lectures. The chairman of ASPO, Prof. P.A. Voûte, and the co-chairman, Prof. H.N. Caron, were together with us all the time and they were very helpful and hospitable. They and all the lecturers from various countries were very friendly and encouraging all through the course. The first day of the course was very busy and dedicated to detailed lectures concerning basic tumour biology. At the end

of the day we were really tired - some of the participants had just arrived the same morning - but glad to be there and meet many colleagues from various countries. The participants tried to know each other during the coffee breaks and lunch time glancing at the badges. The positions of the participants varied considerably from recent graduates from the medical school to some senior paediatric oncologists. I believe, in such an international course, the first session could have been an introductory one such that the participants would know each other and the whole group better.

On the second day of the course the participants felt more familiar with each other and the environment. As far as I noticed, in this course most of the participants were clinicians. So, on the following days, interaction with the lecturers and contribution of the participants improved since the following lectures were more clinically oriented. Case discussion sessions in the afternoons of the second and the third days deserve special mention in that sense since the presented cases and their problems were quite familiar to all of us. During the discussion of the challenging cases, contributions and questions by our senior colleagues and the participants made me feel ►

like I was in the hot tumour board meetings in our hospital. I believe there should be more well organised similar interactive sessions in such postgraduate courses. The last day of the course was also very informative concerning the development of new drugs in paediatric oncology which we were highly interested in.

The scientific program covered nearly all common childhood cancers. Some of the lectures, especially those on the first day, were quite sophisticated and current, while, we were disappointed by the contents of some of the lectures in the following days which were hardly up-to-date and they only delivered classical basic knowledge which we can read from any textbook. In some lectures, the lecturers focused largely on their own studies or field of interest which lead to occasional loss of interest. One separate booklet was handed for each day of the course which included many recent useful reviews related to the subjects of that day. Summaries and slides of some of the lectures were missing in the booklets. I believe, it would be better for the participants to receive all the contents of the booklets and the slides of the lectures on CDs. On the fourth day of the course we were happy to have free time in the afternoon during which I had a tour around the city center on foot and took nice pictures. In the evening of the same day, all the participants and the lecturers of the course enjoyed a nice dinner party on boats going through the canals and watching fascinating Amsterdam. The food and drinks were delicious and chat with new friends was very enjoyable. Finally, it was time to say good bye after a very busy 5 days. We thanked Prof. Caron and Prof. Voûte for the course and their hospitality. Everybody was happy to be in Amsterdam

and attend such an intensive and informative course and meet people from many different countries. We exchanged e-mail addresses and expressed our wishes to meet again.

**Bilgehan Yalçın, M.D.,**  
**Dept. of Pediatric Oncology,**  
**Hacettepe University Institute of Oncology**  
**06100, Ankara-TURKEY**  
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## ASPO MASTER CLASS 2005

Amsterdam School of Paediatric Oncology (ASPO) organizes its MASTER CLASS 2005 from 10-15 January 2005 in Conference Hotel "De Baak", Noordwijk aan Zee in The Netherlands.

We hope that many of you will apply for this exciting and stimulating master class. Also people outside SIOP can apply, so please give this information to anyone who might be interested.

Deadline for application is: 1st OCTOBER 2004.

Your responses are welcome at our website: [www.aspo-ekz.nl](http://www.aspo-ekz.nl) or at this email address: [aspo@amc.uva.nl](mailto:aspo@amc.uva.nl)

**prof.dr. H.N. Caron**  
**prof.dr. P.A. Voûte**

## Future Courses, Congresses and Meetings

### ANZCHOG 2004 CONFERENCE

Date: JULY 8-11, 2004  
Venue: HYATT REGENCY COOLUM, SUNSHINE COAST  
QLD, AUSTRALIA

For more information, contact:

SAPMEA Conventions  
68 Greenhill Road, Wayville SA 5034  
Tel: +61 8 8274 6060  
Tel: +61 8 8274 6053 [direct]  
Fax: +61 8 8274 6000  
Email: [crickards@sapmea.asn.au](mailto:crickards@sapmea.asn.au)  
Web: [www.sapmea.asn.au](http://www.sapmea.asn.au)

### INTERNATIONAL SCIENTIFIC CONFERENCE ON CHILDHOOD LEUKAEMIA INCIDENCE, CAUSAL MECHANISMS AND PREVENTION

Date: SEPTEMBER 6-10, 2004  
Venue: THE CONFERENCE CENTRE, CHURCH HOUSE,  
DEAN'S YARD, WESTMINSTER, LONDON, UK

For more details and registration, contact:

E-mail: [bookings@leukaemiaconference.org](mailto:bookings@leukaemiaconference.org)  
Web site : [www.leukaemiaconference.org](http://www.leukaemiaconference.org)

## **HISTIOCYTE SOCIETY XX ANNUAL MEETING**

Date: SEPTEMBER 12-14, 2004

Venue: STOCKHOLM, SWEDEN

For information, please contact:

E-mail: [HistioSociety@aol.com](mailto:HistioSociety@aol.com)

Web: [www.histio.org/society](http://www.histio.org/society)

## **XXXVI ANNUAL SIOP MEETING**

Date: SEPTEMBER 16-19, 2004

Venue: OSLO, NORWAY

For information, please contact:

Congrex Holland B.V.

P.O. Box 302

1000 AH Amsterdam

The Netherlands

Tel: +31-20-5040 200

Fax: +31-20-5040 225

e-mail: [congreg@congreg.nl](mailto:congreg@congreg.nl)

## **PEDIATRIC HEMOSTASIS AND THROMBOSIS UPDATE**

Date: OCTOBER 1-2, 2004

Venue: SUTTON PLACE HOTEL,  
TORONTO, ONTARIO,  
CANADA

Study Credits:

Royal College of Physicians & Surgeons of Canada

AMA Category 1

European Accreditation Council for Continuing Medical Education

This course will be of interest to pediatric hematologists/ oncologists, pediatric hematology/oncology fellow and residents, nurse practitioners and specialists working in the field of pediatric Hemostasis and Thrombosis.

For more information, please contact:

Alison Soares

Continuing Education, Faculty of Medicine University of Toronto

500 University Avenue, Suite 650

Toronto, Ontario M5G 1V7

Telephone: + 1 (416) 978-4957

Fax: +1 (416) 971-2200

## **UICC WCCO 2004-UICC WORLD CONFERENCE FOR CANCER ORGANISATIONS**

Date: NOVEMBER 16-19, 2004

Venue: DUBLIN, IRELAND

For more information please contact:

Ms. O. Ryan

Irish Cancer Society

5, Northumberland Road

Dublin 4, Ireland

T: +353 1 231 0500

F: +353 1 231 0555

E-mail: [WCCO2004@IRISHCANCER.IE](mailto:WCCO2004@IRISHCANCER.IE)

## **ASPO MASTER CLASS 2005**

Date: JANUARY 10-15, 2005

Venue: HOTEL "DE BAAK", NOORDWIJK AAN ZEE,  
THE NETHERLANDS

For more information, please check the web site:

[www.aspo-ekz.nl](http://www.aspo-ekz.nl)

## **XXVIème JOURNEE D'ONCOLOGIE PEDIATRIQUE LES TUMEURS DU NOUVEAU-NÉ ET DU NOURRISSON**

Responsable : Dr Laurence BRUGIERES

Date: LUNDI 31 JANVIER 2005 DE 9H À 17H30

Venue: INSTITUT GUSTAVE ROUSSY-ESPACE MAURICE  
TUBIANA 39, RUE CAMILLE DESMOULINS  
VILLEJUIF, FRANCE

Comité d'organisation : Dr Olivier HARTMANN – Dr Laurence BRUGIERES – Pr Gilles VASSAL

Public concerné :

Pédiatres, pédiatres oncologues, chirurgiens pédiatres, néonatalogistes, infirmières, puéricultrices, et autres personnels soignants.

Pré-programme :

Données épidémiologiques et biologiques récentes.

Le diagnostic d'une tumeur à cet âge de la vie : tumeurs cérébrales et tumeurs des parties molles.

Le point sur le dépistage du neuroblastome.

Le nouveau-né hospitalisé en oncologie pédiatrique : soins, prise en charge de la douleur et les conséquences au sein du milieu familial.

Les particularités de la chimiothérapie.

Informations pratiques :

Exposés et cas cliniques interactifs.  
Un polycopié est remis aux participants.  
Inscriptions par correspondance jusqu'au 20 janvier 2005  
Nombre de participants limité.  
Lieu : Institut Gustave Roussy – Espace Maurice Tubiana  
39, rue Camille Desmoulins – 94800 VILLEJUIF

Droits d'inscription :

Médecins en activité : 120  
Médecins en formation (justificatif demandé) : chefs de clin-  
iques, internes, résidents, boursiers : 60  
Personnel paramédical : 60  
Forfait comprenant : exposés, polycopié, déjeuner-buffet,  
pauses.  
Enseignement pouvant être pris en charge par l'employeur  
dans le cadre de la Formation Professionnelle Continue.

Renseignements et inscriptions :

Anne-Marie RIVIERE  
Secrétariat de l'Enseignement  
INSTITUT GUSTAVE ROUSSY – VILLEJUIF (France)  
Tél : 33 1 42 11 51 44  
Fax : 33 1 42 11 52 48  
E-mail : ariviere@igr.fr

#### **6TH INT. SYMPOSIUM AND EXPERT WORKSHOPS ON LEUKAEMIA AND LYMPHOMA**

Date: MARCH 17-19, 2005  
Venue: AMSTERDAM, THE NETHERLANDS

For more information please contact:

Ms. I. van Baardwijk  
PAOG Course and Congress Organisation  
VU University Medical Center  
E-mail: paog@vumc.nl  
Web: www.hemonc.nl  
Email: SCMCmud@online.sh.cn

#### **XXXVII ANNUAL SIOP MEETING**

Date: SEPTEMBER 21-25, 2005  
Venue: VANCOUVER, CANADA

For more information please contact:

Malachite Management Inc.  
Tanis B. Steward  
Phone : +1 604 874 4004  
E-mail: tanis@malachite.mgmt.com

#### **4TH SIOP ASIA CONFERENCE**

Date: 2006  
Venue: SHANGHAI, CHINA

Information can be requested at:

Prof. Wang Yao-Ping  
Chairman, Organizing Committee  
4th SIOP-Asia Conference  
Dept. of Pediatric Hematology-Oncology  
Shanghai Children's Medical Center  
Shanghai, China  
Telephone : +86-021-58732020  
Fax : +86-021-58393915

#### **7TH CONTINENTAL MEETING OF THE SIOP IN AFRICA**

Date: 2006  
Venue: MARRAKECH, MAROCCO

For more information please contact:

SIOP Secretariat  
Tel: +31 40 269 75 44  
E-mail: secretariat@siop.nl

#### **XXXVIII ANNUAL SIOP MEETING**

Date: SEPTEMBER 19-23, 2006  
Venue: GENEVA, SWITZERLAND

For more information please contact:

SIOP Secretariat  
Tel: +31 40 269 75 44  
E-mail: secretariat@siop.nl

#### **5TH SIOP ASIA CONFERENCE**

Date: 2008  
Venue: AL-KHOD, SULTANATE OF OMAN

For more information, please contact:

Prof. Zakia Al Lamki or Prof. Mathew Zachariah  
5th SIOP-Asia Conference  
Associate Professor & Head, Child Health Department, Sultan  
Qaboos University, College of Medicine, P.O. Box 35, Al-  
Khod, Sultanate of Oman, Postal Code 123,  
Telex : 5602 SQU ON Cable: Jami'ah  
Telephone : +968-51537,  
Telefax : +968-513419 or +968-515136  
Email : zakiya@squ.edu.om OR mathewz@omantel.net.om

# ASTRO

## MARK YOUR CALENDAR



### Future ASTRO Annual Meetings

**46th Annual Meeting**  
**Georgia World Congress Center**  
Atlanta, Georgia   
October 3-7, 2004



**47th Annual Meeting**  
**Colorado Convention Center**  
Denver, Colorado  
October 16-20, 2005



**48th Annual Meeting**  
**Pennsylvania Convention Center**  
Philadelphia, Pennsylvania  
November 5-9, 2006



**49th Annual Meeting**  
**Los Angeles Convention Center**  
Los Angeles, California  
October 27 - November 1, 2007

**50th Annual Meeting**  
**Baltimore Convention Center**  
Baltimore, Maryland  
October 5-9, 2008



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