

# Notes on the Development of PODC in SIOP

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## Introduction

PODC means Pediatric Oncology (**PO**) in Developing Countries (**DCs**) and these are defined each year by the World Bank and divided up in low-, lower-middle- and upper-middle-income countries, according to their mean per capitum income.

The true history of PODC will probably never be written, because it is too complex and because too many people were and are involved.

In this review the history of PODC in SIOP is described as seen by the former chairman of SIOP's PODC Committee (1993 – 2010).

## SIOP before 1990

**SIOP**, the **International Society of Pediatric Oncology**, was founded in **1968** by predominantly young PO specialists eager to develop PO in Europe and to have it recognized as a subspecialty of Pediatrics.

The profile of **Odile Schweisguth**, head of the first Pediatric Cancer Unit (.PCU) in Europe at the Institut Gustave Roussy in Paris, predisposed her to become the first leader of the new society. The fact that **SIOP** stands for **Société Internationale d'Oncologie Pédiatrique** demonstrates, that the roots of SIOP are French, and clearly distinct of other roots of PO.

The **first real confrontation of SIOP with PODC** occurred in **1984**, when J. Martinez-Mora, host of **SIOP 16 in Barcelona**, couldn't reimburse the many representatives of DCs he had invited, because the sponsor who promised to do so failed, and SIOP had to pay.

In **1986** the **membership of SIOP in the Federation of European Cancer Societies (FECS)** was **suspended** because SIOP did not conform to the rules of FECS, in particular SIOP's annual meetings were not only held in Europe. To circumvent this problem, SIOP first created **SIOP Europe (SIOPe) in 1986, and, one year later, the five other continental branches** (Africa, Asia, Latin America, North America and Australia/Oceania).

## The globalisation of SIOP and the start of PODC within SIOP

Up to **1990** SIOP was an European – North American society with 335 members but only 10% from DCs. After the fall of the wall in Berlin on November 9, 1989, and under the presidency of T. Vouïte, the **Board decided at SIOP 22 in Rome, to open its doors to the world.**

In the following an attempt is made to describe in some detail how PODC started and how it developed.

At the **15th International Cancer Congress in Hamburg 1990**, N. Gad-el Mawla from Cairo and G. Prindull from the European Society of Pediatric Hematology and Immunology

(ESPHI) organized a symposium on PODC. After this symposium representatives of the American Society of Hematology (ASH), ESPHI, the National Cancer Institute in the US (NCI USA) and SIOP founded an **International Working Group (IWG)** for PODC and decided to promote **twinning** (mutual cooperation of PCUs in developed countries with PCUs in DCs). Together they established a list of existing/planned twinning projects. Also in 1990, in February, came out **SIOP NEWS** No.1, edited by J. Ninane.

For **SIOP 23, 1991 in Rhodes**, Greece, the host, T. Tzortzatos Stathopoulos, managed to provide **free attendance for 30 colleagues from the former USSR**. At this meeting a group interested in promoting PODC established a list of 9 activities or topics related to PODC for submission to the Board.

For **SIOP 24, 1992 in Hannover**, H. Riehm invited and supported **over 160 delegates from DCs**. In a guest lecture on leukemia in India, M. Chandy described the **influence of the socioeconomic standing** of a family on outcome: 80% of children with ALL had no, 15% limited, and only 5% good access to care. At this meeting the Board decided to establish a **scholarship program for young doctors and nurses**.

**On January 4, 1993 the Board decided to establish a PODC group of 4** to assess the role of SIOP in DCs, to develop a 5 year plan, and to find mechanisms for the evaluation of scholarship applications.

For **SIOP 25, 1993, in San Francisco**, the availability of PODC scholarships was announced, and, of the applications received, 37 were selected by the Scientific Committee and the PODC group for support. At **SIOP's first one-day PODC Symposium** many aspects of PODC were discussed, and a summary of the symposium published in the SIOP NEWS. In addition, efforts were made to **establish a PODC net** by collecting the coordinates of people working in PODC present, and around the globe. **For all subsequent annual SIOP meetings a PODC program was developed and detailed reports were published in the SIOP NEWS. Also, for all future annual meetings at least 30 scholarships were financed by SIOP.**

In 1994 P. Hesseling organized the **1st SIOP Africa Meeting in Stellenbosch, South Africa**. Only North and South Africa had some structures for PO, the sub-Saharan countries had practically none. The outlook for children with Burkitt's lymphoma (**BL**) was dismal.

At **SIOP 26 in Paris in September 1994**, a **one-day PODC Symposium was focused on PCUs**, lack of trained personnel and diagnostic as well as supportive care facilities, neutropenia and infection, surgical complications and Twinning. Of 51 scholarships 11 went to Eastern Europe, 8 to the ex-USSR, 14 to Asia, 11 to Africa and the Near East, and 7 to Latin America.

For PODC, at **SIOP 27 in Montevideo 1995**, abstract forms corresponding to Wiley's standards and with an option to apply for a scholarship, were sent to all major Latin American institutions treating children with cancer and to all members of the Brazilian Pediatric Oncology Society (**SOPOBE**) and to all members of the Latin American Pediatric Oncology Society (**SLAOP**). Of 91 abstracts returned, 20 were selected for oral presentation, 47 for posters and 5 for publication only. All of these 72 abstracts were subsequently published separately in the Proceedings of the meeting in Medical and Pediatric Oncology (**MPO**). Over 30 scholarship applications were approved. **Highlights of the PODC Workshops** were reports on antibiotics in neutropenia reducing lethal infections in children with ALL from 20 to 5%; on 3 chemotherapy (**CT**) courses being as effective as more CT or CT plus

radiotherapy (**RT**) in children with low stage Hodgkin's disease; on good results obtained with modified B-NHL/B-ALL BFM 71 and AML/BFM 87 protocols in Argentina; on the importance of early diagnosis and referral of children with retinoblastoma. At the following round-table discussion representatives of the IWF and Confederation of Childhood Cancer Parent Organisations (**ICCCPO**) underscored the importance of early diagnosis, rapid referral, centralisation of treatment, education and clinical research, as well as the need for registration and evaluation of clinical observations. At the General Assembly the **„Montevideo Document on Pediatric Oncology in low-income countries“** was accepted.

In **March 1996 the 2nd SIOP Africa meeting at the Mena House in Cairo** attracted more than 500 delegates from more than 23 countries. The actual state of the art, and minimum requirements for the treatment of pediatric cancers, were discussed.

## **SIOP develops its own PODC studies**

Since 1968 the main income of SIOP was from membership fees. To collect money for SIOP or PODC „at home“ entered in competition with national fundraising for cancer and was considered, but never done. With the globalisation of SIOP and the increasing visibility of PODC, this slowly changed. Institutional and a few private sponsors started cautiously to support SIOP's PODC activities and this opened up new perspectives.

In **May 1996**, S. Lie, the president of SIOP, organized, with the support of the Norwegian Cancer Society, a **strategic meeting in London to better define the role of SIOP in DCs**. He invited representatives from the World Health Organization (**WHO**), the „Union Internationale Contre le Cancer“ (**UICC**), the **NCI USA**, **ESPHI**, the American Society of Pediatric Hematology and Oncology (**ASPHO**), but also **specialists from DCs**. At this meeting it was decided to invest SIOP's limited resources in three new projects: **the Malawi's BL project, the Indian National Education project, and the „White Book“**.

**The Burkitt's Lymphoma (BL) project** was started in Malawi with the idea, that if it functioned there, it could function anywhere in sub-Saharan countries. The challenge was to develop a guideline for an affordable, short treatment with limited toxicity, yielding an overall survival rate of approximately 50%. It took almost 20 years to refine and test these recommendations, but the effort was worthwhile and the goal to cure about 50% of the children in Black Africa with BL was reached.

**The Indian National Training Program in Practical Pediatric Oncology (INTPP.PPO)** started with a trainer's work-shop 1997 in Mumbai under the auspices of SIOP and the Pediatric Hematology/Oncology Chapter of the Indian Academy of Pediatrics. A 2-day standard training module was adopted by 44 pediatric oncologists from all over India. During the following years more than 30 work-shops based on the initial, and later, on a modified module, were held throughout the country. Starting in 2009 half-day courses for up to 75 participants were given in all parts of India, always emphasizing, that childhood cancer was curable if diagnosed early and transferred rapidly to a specialized center. The INTPP-PPO program brought together a large body of pediatric cancer specialists and facilitated the formation of the Indian National Pediatric Oncology Group (**INPOG**).

Many people were involved in the **White Book** project. The idea was to collect treatment guidelines adapted to countries with limited resources, but in view of the big variation of local circumstances and influencing factors, the first recommendations were published only in 2009 and the following years.

**SIOP 28 in Vienna, October 1996**, attracted over 1600 active participants, including nurses and parents. The main theme was bone tumors, but in view of the many representatives of Eastern countries, the PODC program was focused more on leukemias and lymphomas. It was in Vienna that the Board elected B. Agarwal, R. Barr, G. Henze, P. Hesselting, S. Lie, I. Magrath, G. Masera, G. Schellong and H.P. Wagner, and in 1997 2 additional members, W. Crist and Y. Ravindranath, to form **the core PODC committee**. In order to open the PODC committee to all people interested in PODC, SIOP members were invited to become „**PODC Consultants**“, if they were willing to contribute, and 34 did. It was decided, furthermore, that the continental presidents should be members of the PODC Committee „ex officio“. **The new PODC Committee** met for the first time on October 3, 1996. At the General Assembly in Vienna, it was announced that G. d'Angio had become the new editor of SIOP's official journal, the Medical and Pediatric Oncology (**MPO**).

The main theme of **SIOP 29 in September 1997 in Istanbul** („where the continents meet“) was „Lymphoma in Childhood“. Regarding PODC, the scholarship program was reviewed critically and with regard to the White Book, the question was raised, if 3 types of guidelines should be developed, one for patients of parents who understand what cancer is and who can pay, one for patients of parents who partially understand but cannot pay, and finally patients of parents who do not understand and cannot pay. At the general assembly a reduction of membership fees for members from DCs was accepted.

**In October 1997** a National Meeting on Malignant Tumor in Children convened at the Capital University of Medical Sciences **in Beijing**, and simultaneously the **Chinese Pediatric Oncology Group**. The latter **approved a protocol for ALL and one for BL**. Three SIOP PODC members acted as consultants.

At **SIOP 30 in October 1998 in Yokohama**, there were 27 oral PODC presentations, the majority on neuroblastoma, the main theme of the meeting, In general, **a high percentage of deaths due to infection and a high rate of absconders** were reported. Among the 36 PODC posters there was one getting a prize for stating that IDA-FLAG was not a cost-effective therapy for relapses of leukemia in low-income countries! **Central issues in PODC were education, drug supply, development of PCUs and national PO networks..**

## **PODC on the eve of the Millenium**

In September **1999, in Montreal**, there was a **joint annual meeting of SIOP (SIOP 31) and ASPHO**. At the PODC Meeting PODC activities around the World were reviewed: in China the Chinese Pediatric Oncology Group, founded in 1997, had extended its activities with the help of the NCI USA and SIOP to 12 institutions and was running clinical trials with 20 physicians trained in the USA for data management and tumor registry work; in India the INTPP-PPO and an adapted ALL protocol were successful, in Indonesia an ALL protocol was tested; in Africa SIOP's BL studies were evolving and in France, at the „Journées franco-africaines“ the base for a new multicenter PODC study group was laid; in Europe German twinning programs for ALL with Russia and the Ukraine (**GPLLU: Ukrainian Cooperative Group** for the treatment of leukemias and lymphomas, since 1993), as well as a Swiss program with Minsk were running; in Italy the 13th anniversary of the Mascota program between Monza and Managua, Nicaragua, and the third anniversary of **MISPHO** (Monza's International School of Pediatric Hematology and Oncology) was celebrated; in Central America **AHOPCA** (Central American Association of Pediatric Hematology and Oncology)

was founded in 1998. Obviously this review was incomplete: neither the activities of the St. Jude International Outreach Programme nor the PODC activities of the NCI USA and other important institutions were mentioned. Besides an ICCCP/PODC meeting, there was another ICCCP/PODC Symposium called „Development of an Alliance of Stakeholders, Parents and Health Professionals Worldwide: Investing in the Future“.

At a CME meeting in **Vellore, India in January 2000**, „a good symptom palliation for all and efforts to gradually increase the percentage of children with cancer who have access to curative therapy, above the current level of 10-15%“, was postulated.

At the **first SIOP Asia meeting in Singapore in April 2000** it was decided to develop an Asian PO network comprising all national PO organisations, to support the formation of new parents groups and to edit a SIOP Asia newsletter with 2 issues/year.

At the **4th SIOP Africa meeting in May 2000 in Sun City** (North of Johannesburg) organized by the South African Children's Cancer Study Group (SACCSG), the South African PO nurses had their first meeting and a South African Parent's Group was founded.

**SIOP 32 in Amsterdam, in October 2000**, was visited by **Queen Beatrix**. 160 participants from DCs received a scholarship or another support. At the PODC Meeting **IDA**, the International Dispensary Association, selling high quality drugs since 1972 to non-profit organisations at reasonable prices; and new twinning programmes (Bolivia-Bergamo/Monza and Cuba-Padua, both since 1998, and Paraguay-Modena and Republica Dominicana-Bologna, both since 1999) were presented. The International Cancer Treatment and Research Organization (**INCTR**), supported by the NCI USA, UICC and the Institut Pasteur in Brussels, had 2 offices since April 1st 2000: one at Pasteur in Brussels and one in Rockville, Maryland, USA. INCTR promotes education and research in DCs: Brazil: osteosarcoma; NCI Cairo: pediatric leukemias; King Faisal Hospital, Riyadh, Saudi Arabia: tissue bank, molecular oncology; Harare, Zimbabwe: new; Shoukat Khanum Memorial Hospital, Lahore, Pakistan: new; Katmandu, Nepal: new; Chennai Cancer Institute, Chennai, India: cancers of cervix, breast and oral cavity, pediatric leukemias; Tata Memorial Hospital, Mumbai, India: pediatric leukemias and lymphomas; Singapore (NHL), and Childrens Medical Center, Shanghai, China: molecular characterization of ALL. In Tehran, **MAHAK**, a non-governmental organisation founded in 1990 provides free medical care and psychosocial support to children with cancer and their families, and is building a rehabilitation facility and a multidisciplinary day-clinic. **GFAOP**= Groupe Franco- Africain d'Oncologie Pédiatrique, under J. Lemerle, since October 2000, comprises 7 pluridisciplinary, PO centers in Tunis, Alger, Rabat, Casablanca, Dakar, Yaoundé and Tananarive (Madagascar).and will start with 2 protocols, one for BL and one for Wilms's tumor. **CURE**, an International Consortium for Cure of Childhood Cancer, established by W.T Newton Jr., had its 1st meeting on May 21, 2000, in New Orleans to establish a plan for a national childhood cancer program in China. The **Saint Siluan Warning signs for Cancer in Children** were developed by SACCSG. **Change from IMEDEX to CONGREX**, a professional conference organizer, to start in Porto 2002.

In **February 2001** an **International Seminar on Pediatric Hematology and Oncology** was organized in **Dhaka**, Bangladesh.

**New Challenges, new Hopes**

One month after 9/11, in **October 2001, SIOP 33** opened in **Brisbane Australia**. The meeting and the PODC activities went well. It was announced that the Koningin Wilhelmina Fonds had decided to vote 1% of the annual expenditures to oncology in DCs..A consequence of the visit of Queen Beatrix at SIOP 32?

**On January 19, 2002**, The Board evaluated the present situation and discussed the strategy for the next 5 years. It was decided to strongly support PODC and the development of the continental structures.

**On March 26, 2002, Odile Schweisguth died at age 89.**

**On May 26-29 2002**, the **5th SIOP Africa meeting** took place in **Yamoussoukro, Ivory Coast**, just 4 months before a rebellion came up in the North and West and divided the country in 3 parts. (1st Civil War). At this meeting the great need for well trained PO nurses to run PCUs was brought forth.

At **SIOP 34 in Porto, September 2002**, it was realized that **SIOP cannot fulfill the requirements to conduct clinical trials according to the guidelines for Good Clinical Practice (GCP)** as developed by the the International Conference on Harmonisation of Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH), and adopted in July 1986 by the European Union (E6). The question arose, what this meant, in terms of liability, for SIOP-labeled PODC treatment guidelines.

The **2nd SIOP Asia Conference in Delhi in November 2002** was under the epigraph „Childhood Cancer is Curable“. All relevant topics of PO including parental activities were reviewed .

At the **INCTR Annual meeting on May 31st 2003 in Brussels** the motto for BL in Black Africa was: „A good protocol is not enough, you have to have the right nurses to make a good use of it“.

At **SIOP 35 in Cairo, October 2003**, for the first time, **practically all PODC abstracts were integrated in the main stream program**. At the General Assembly it was announced i) that **starting January 1st 2004, MPO will become Pediatric Blood and Cancer (PBC)** with R. Arceci as editor in Chief; ii) that the **SIOP Council** (= Board and Continental Presidents) was formed; and iii) that a **new rotation of the annual meeting venue** was introduced to increase the number of meetings in DCs.

In December 2003, in San Diego, a Group of ALL specialists approved to submit **the Ponte di Legno mission statement**, „The Right of Children with ALL to Full Access For Essential Treatment“ to WHO and to publish it in key medical journals.

**On January 16 2004, the Board and the Scientific Committee** had a meeting/teleconference to **discuss the role of SIOP in clinical trials**.

**On May 1st 2004 the New EU Directive on GCP became law.**

Just prior to the **3rd Asia Conference in Dhaka in February 2004** (375 registrations, 113 scholarships, 65 abstracts, 50 oral presentations), a UK party under T.Eden visited centers delivering care for children with cancer, the **ASHIC shelter** in Dhaka run by parents and volunteers and the new PO ward of the Bangabandhu Sheikh Mujib Medical University in

order to test **evaluation forms** used to formulate recommendations for the further development of PO in a city or country.

On **April 2 2004 SIOP's PODC activities** were **presented to the COG International Outreach Task Force** in Washington DC, USA,.

At the **6th SIOP Africa Meeting in May 2004 in Blantyre, Malawi**, a visit to the pediatric oncology ward and the outpatient clinics at the Queen Elisabeth II Hospital, illustrated the overcrowding of the wards, the shortage of doctors and nurses, the limitations of supportive care and the challenges set by malnutrition, parasites and infectious diseases, in particular AIDS and tuberculosis. The **Malawi BL project, actually testing cyclophosphamide monotherapy** and aiming at a cure rate of 40-50% with costs of drugs of less than 50 US\$/patient, was simultaneously used in 3 other places: two in Cameroon and one in Ghana.

At **SIOP 36 in Oslo, in September 2004**, the best component of the PODC Program was a round-table discussion with ICCCP on **Twinning: Two Worlds – One family**, and the elaboration of guidelines for Twinning.

**February 15 2005** was the International Childhood Cancer Day „**Through my Eyes**“, a day in the life of children with cancer around the World.

**The 2nd Latin America Continental Meeting and the 20th SLAOP Meeting in Campo Grande, Brazil, in April 2005**, brought together representatives from SLAOP, St. Jude Children's Research Hospital, COG and SIOP to discuss experiences with international studies and to **evaluate modalities for a cooperation between centers of excellence in South America and COG**, permitting selected PO centers to put patients on COG protocols..

In May 2005 the first International Congress of the Pan Arabic Society of Pediatric Oncology (**PASPO**) was held in Annaba, Algeria.

## **PODC comes up with results**

At **SIOP 37 in Vancouver, September 2005**, reports from all over the World demonstrated that **more children with cancer in countries with limited, even very limited resources were cured than ever before**. This was not the merit of one organisation or group, this is the merit of a large, international network of closely cooperating institutions. This network is so large, that it is difficult to describe it, because so many people are involved. An interesting aspect of this **network** is the fact, that it **has been developed with a minimum of resources**, mainly because so many people worldwide have given of their time and energy to improve PODC, without any remuneration. This is also true for the members of SIOP who have worked for PODC and who have brought it up, within 15 years, to an internationally known organization. SIOP has hosted and supported PODC in the best possible way.

In Vancouver the **reports of the continental presidents** provided an excellent overview of PODC activities.. Besides those alluded to previously, activities of the Pediatric Oncology Study Group in Hong Kong and of the Guangzhou Childhood Leukemia Study Group and the Guangdong Province Pediatric Oncology Society were mentioned, and also those of the Australian and New Zealand Children's Hematology and Oncology Group (**ANZCHOG**) serving Papua New Guinea, Fiji, Tonga and others, using telemedicine and promoting education.

One important warning was also heard in Vancouver: **clinical research in low-income country should be centered on reducing abandonment and death from toxicity, rather than on selection of the optimum CT program.**

In view of the rapid growth of PODC a **reorganisation of the PODC Committee was proposed and accepted, and subsequently submitted to the Board.** It was decided to take forward important topics by forming **Working Groups (WGs)**, and to have the chairpersons of these WGs form the core committee. Basically all SIOP members could become PODC consultants, if they join an existing WG, or set up a new one..

Beginning with the meeting in Vancouver, a **collaboration between Cure4kids and SIOP** was established for keynote lecture and educational book downloads and other professional information between meetings.

At the **February 2006 meeting in Managua, Nicaragua, the 20 anniversary of the La Mascota program** it was estimated that among the 2 million children <14 about 260 new childhood cancer cases/ year would be observed, and that of these approximately 70% reach the Hospital Infantil Manuel de Jesus Rivera, „La Mascota“, and that of these 70% about 50-60% survive, overall about 40%.

At the **7th SIOP Asia Meeting in March 2006 in Marrakech**, the following estimations for Morocco were made: 10,5 million children <15, approximately 1350 new cancers/year, of these 60-65% reach one of the 2 PCUs and of these about 70% get reasonable treatment and of the latter 50-60% survive, overall about 25%.

At the **4th SIOP Asia Conference in April 2006 in Shanghai** (334 registrations), the following results were communicated: at the Beijings Children's Hospital the overall event-free survival for 428 patients with ALL seen 1998-2003 (235 standard risk, 193 high risk) was 76%. Of 224 children with ALL seen 1998-2003 at Shanghai Children's Medical Center 38 left without therapy and 28 absconded within less than 15 days. Of the remaining 10 died due to complications, 8 did not attain CR and 40 relapsed: overall survival 45%. Two new parents groups were formed in Shanghai.

**Good news at SIOP 38 in Geneva, in September 2006**, was to hear that the „**My Child Matters**“ (MCM) Campaign, a collaboration of **Sanofi Aventis** with UICC, ICCCP, St. Jude Children's Research Hospital, INCTR, the NCI USA and the International Agency for Research on Cancer (**IARC**) supported 14 projects in 10 countries and that 6 other projects were to be added in 2007. Health research workers from a firm called **SanoSphere** visited each country funded, and analysed population and country demographics, health care delivery and financial arrangements, in order to increase the sustainability of aid and support for long term success. Good to hear was also that ICCCP had created the **World Childhood Cancer Foundation** later **World Childhood Cancer**, and that a consortium of UICC, SIOP and IPA (International Pediatric Association) was pushing **the essential drug formulary** as part of a global effort to address the issue of drugs for children and young adults, while WHO was revisiting their essential cancer drug list.

**October 2006: First International Conference on Childhood Cancer in Tehran, Iran:** Childhood Cancer represents an emerging health problem in Iran with its large young population.

**December 5, 2006:** Afghan Group for Pediatric Oncology (**AGPO**) established in Kabul.

**January 31st 2007: Essential Drugs Meeting in Amsterdam** with representatives of WHO, IPA, SIOP, INCTR and ICCCP: the generation (and eventual modifications) of the list of essential drugs (and also of the list of drugs for children) were discussed..

**SIOP 39, Mumbai, November 2007:** Prior to the meeting, „hands on workshops“ and during the meeting a special PODC program attracted many delegates. The special PODC program comprised 3 sections: one on **Childhood Cancer Registration** with a review of the actual status in India and recommendations from the St. Jude Cancer Research Hospital; one on **Supportive Care** focusing on febrile neutropenia and palliative care ; and finally one on the **establishment of multicenter, cooperative trial groups**, in India, Latin America and elsewhere, in order to participate in COG's outreach program or in other international trials. **The Continental Presidents** reported on the new SIOPE office in Brussels embedded within the European Cancer Organisation **ECCO**, formerly FECS, and discussions concerning **GCP and EMEA**; the use of BL treatment guidelines with risk adapted initial treatment with low-cost, not too toxic cyclophosphamide-based therapy in Western Cameroon, the development of national PODC networks and regional meetings in Asia, **child and adolescent cancer services in the Pacific** by POSG; current **concepts of the Atomic Energy Commission IAEA regarding pediatric radiation oncology in countries with limited resources**.

„In Quest of a Complete Cure“ was the theme of the **5th SIOP Asia meeting in Muscat, Oman**, in February 2008, which was run in cooperation with the Middle East Cancer Alliance **MEKKA**.

At the **8th SIOP Africa Meeting in Tunis**, in **May 2008**, „The basic principles of cancer genetics“, pediatric surgery, pediatric radioation, pain, anemia and febrile neutropenia were discussed and an overview of PODC activities given.

## How Good is the PODC Machinery?

In 1990 SIOP had no PODC program and no structures for PODC and SIOP was not sure whether it should be concerned with PODC or not. Was it the fall of the wall in Berlin or his Dutch chromosomes that pushed T.Voûte, president of SIOP from 1990 – 1992, to opt for the World instead of only Europe and North America? His argument, that if SIOP wanted to be a real international society for pediatric oncology, it had to open its doors to the approximately 80% of children with cancer who lived outside Europe and North America and who were in great need of the know-how that had been accumulated in the „West“, was very strong and appealing, last but not least because the fight against childhood cancer had been so successful in North America and Europe. What it meant however, to opt for PODC was probably greatly underestimated: who would have predicted that all the things listed above and many more could happen, and that within less than 20 years such a complex, worldwide organisation would arise?

### The PODC Machinery:

Visible PODC **activities** of SIOP are:

- Platforms: PODC Committee Meetings, SIOP Congresses/Conferences (with Symposia, Round-tables, Workshops, Poster sessions), SIOP News, International Notes;
- Scholarships, reduced Congress/Conference fees;
- SIOP membership at reduced rates;
- Promotion of Twinning;

- Standards for training and care;
- Promotion of national PO networks;
- Provision of expertise by faculty members, consultants, etc.;
- Funding of selected projects.

The **structures** behind these activities were/are :

- The PODC Committee with a core group elected by the Board, consultants (members interested in PODC and willing to contribute) and the continental presidents;
- The scientific Committee and the Discipline Groups of SIOP;
- The Continental SIOP Branches with their PODC components (national PO nets, governmental and NG pediatric oncology organisations, childhood cancer registries);
- PODC partners: INCTR, CURE, FAPOG, MISPHO, St. Jude Cancer Research and COG outreach programs, others;
- SIOP Partners like WHO, IARC, UICC, ICCCP, HS, IPSO, ESO, others.

Looking at this machinery the question arises, how much it contributes to solve the problems of PODC and to what extent it supports the vision of SIOP that „**No Child should DIE of Cancer**“. A first step was made with the proposals regarding the **reorganisation of the PODC Committee**. It was stated, that the Core Committee should define parameters for the evaluation of the status of PO in different countries, should evaluate the status, and should translate the results into strategies to improve PO in a given country. A second step were the **analyses of Sanosphere** based on a best possible estimation of the absolute number of children developing cancer each year in a country, the best estimate of the fraction getting treatment and the fraction of treated children surviving. Evaluations along these lines have been performed in all countries where projects of the „My Child Matters“ were funded. Examples are Nicaragua 2006 and Morocco 2006 (see above): only in Nicaragua was the observation long enough to see a clear increase of the overall survival from a very low level to approximately 25% in 20 years!.

Assuming that an increase in PO specialists increases survival, SIOP was successful: in 1990 only 10% of 355 members, in 2008 40% of 1479 members lived outside Europe and North America.

**At SIOP 40 in Berlin, in October 2008** (20000 participants from 140 countries), reports on SIOP's Malawi BL project and others on GFAOP experiences with BL indicated that 50-60% of children with BL could be cured by a low cost, not very toxic treatment, but this did not (yet) influence the percentage of survivors in sub-Saharan, black African countries. In a section of the PODC program it was stated that the great majority of low-income countries are found in Africa, that in many countries not even basic structures required for twinning were available, and that despite the Malawi program and GFAOP the majority of children with cancer had no access to treatment.

Another section of the PODC Program in Berlin was devoted to the **progress of PO in Eastern Countries**. In Eastern Europe there were about 8000 new childhood cancers in a population of approximately 60 million children < 15. Since the end of the communist era the percentage of survivors increased to about the same level as in Western Europe. In the 5 Central Asian countries Kazakhstan, Uzbekistan, Turkmenistan Kyrgyzstan and Tajikistan lived a total of about 18 million children <15, and of these approximately 2200 developed a cancer each year (120/1 million). Of the 300 new cases seen **in Tajikistan, approximately 60% have no access to care**, but of those who have, the 5year survival rate rose from 29 to 47% in 2 decades! In a new twinning program between the Lund University Hospital in Sweden and the National Hospital for Pediatrics in Hanoi, the Vietnam Childhood Cancer Program financed by IKEA, 132 patients were registered during the first 6 months of 2008, but in July 2008 over 50% had already abandoned their treatment..

**At SIOP 41 in Sao Paulo in October 2009** (1649 participants from 86 countries) there were lively discussions concerning the reorganisation of the PODC Committee and the new WGs. The PODC Premeeting consisted of **4 Minisymposia**: Bridging the Atlantic: New Cooperations between Lusophone African Countries (**LAC**) and Brazil; Minimum Requirements for PCUs in DCs; Publishing Pathway Analysis: Targeting how to write, publish and review scientific articles; and Health Care Disparities in the Management of Childhood Brain Tumors in Emerging Countries. In the main stream program, at the **symposium „Achieving Early Diagnosis in Childhood Cancer: Standard, Advantages and Roadblocks“** North American, Latin American, African and Indian perspectives followed by „Are risk-adapted Treatment Strategies for ALL feasible in Developing Countries?“ were presented. Although not unsuspected, it was sad to hear what the reality is in India: **approximately 80% of the children with cancer in India do not reach a PCU, 10% reach one but opt out, 5% get treatment but drop out, and only 5% benefit.** Selected reports of **New PODC Projects/Progress Reports** were: „Childhood Cancer in Rural Egypt: Facts/Challenges“ : ALL treatment at the level 1 PCU of the Menia Oncology Center 300 km South of Cairo serving a rural population of 4,3 millions with support of PO specialists from Cairo, resulted in a 5 year overall survival of almost 50%. Of those who died half relapsed, 30% abandoned therapy and the rest were treatment related deaths; „Cancer Incidence Among Children and Adolescents in Brazil: First report of 14 population-based cancer registries“ covering about 15% of the Brazilian child and adolescent population, the median age-adjusted cancer incidence was 178 per million children 0-14 years old; the **„Practical Manual for the Management of Children With Cancer“** for nurses, physicians and visitors of the SOBO PO ward at the Queen Elisabeth Hospital in Blantyre Malawi with 13 pages on individual tumors and 13 pages of treatment flow sheets allowing an easy documentation of treatment: **a precursor of the „White Book“?**

The theme of the **6th SIOP Asia Congress on Kish Island, Iran, March 2-5, 2010**, was „Best Care and Cure for Children with Cancer“. The presidential symposium was entitled „Asian Landscape“, the closing session „Orient Meets Occident's“, the whole spectrum of PO and PODC was covered, there were about 230 participants from 50 countries.

The theme of the **9th SIOP Africa Meeting in Accra March 10-12, 2010** was „Childhood Cancer in Africa: Improving Access to Care“. There was a **pre-conference workshop on „How to Perform Fine Needle Aspirates“** (39 participants from 6 countries). Interesting topics of the main program were „The Rights of a Hospitalized Child“; „HIV Related Cancers“ and „Stress Management“. Themes of the nurses program (in part with the parents) were „Nutritional Needs“, „End of Life Support“, „Central Venous Access Devices“, „Palliative Care and Pain Control“, „Psychologic Aspects“. At the end **recommendations** regarding „The Way Forward“, training, fund raising, and drugs were formulated. There were 188 participants. About **30 applications for SIOP membership** were received.

At the **International Congress of the Pan Arab Society of Pediatric Oncology (PASPO) in Constantine, Algeria, March 27-30, 2010**, the molecular pathology, diagnosis, treatment modalities and outcome of sarcomas in children and adults were discussed.

## The Reorganization of the PODC Committee and Information Technology (IT) for PODC

**SIOP 42 in Boston, October 21-24, 2010:**

**Pre-meeting PODC Symposia** were organized for

- Management of Children with **Wilms Tumor in Africa**: „the adequate intensity and duration for the African setting remains to be found“ and „survival (around 40%) is lower than in high-income countries mainly due to late presentation (<5% failure to treat with free medical treatment and social support)“ ;
- Management of **Childhood Brain Tumors in Emerging Countries**: main roadblocks: in sub-Saharan Africa 1 neurosurgeon/10 million people, lack of reliable neuropathology, lack of adjuvant therapies (high-dose CT, autologous bone marrow transplantation);
- **Analysis of local outcome information to improve global childhood cancer care: tumor registries and tools for collaboration**: „access to patient-specific information is the foundation for improved care for individual patients“, „tools for international collaboration and communication: [www.Cure4Kids.org](http://www.Cure4Kids.org) hosts more than 1600 online seminars available for download at no cost and on which about 50 online meetings per month are held to discuss patients, protocols and other issues. The technology is available for groups to hold their own meetings, and is designed for groups to function independently, even if they have no connection to St. Jude, which provides the service. The Pediatric Oncology Networked Database ([www.POND4kids.org](http://www.POND4kids.org)) is available to facilitate data management programs and outcome evaluation and is available to users at no cost.“

**New PODC Projects and Updates:**

**Strategies to Improve Care for Children in Sub-Saharan Africa**: a top 10 list of priority interventions recommends that priority be given to interventions that benefit all children like pain control and palliative care, improvement of supportive care and diagnostic facilities; for childhood cancer it is recommended to target cancers that occur relatively common and are curable with a relatively simple and short treatment.

**A Twinning Program: the National Cancer Institute Colombia and the Dana Farber/Children's Hospital Boston** increased the event-free survival rates of children with ALL dramatically by targeted interventions addressing abandonment of therapy and toxic deaths; **Internal Twinning, Working From the Inside Out**: describes working relationship (shared care adapted to local capacities) of the Red Cross War Memorial Children's Hospital (RCCH) in Cape Town, South Africa with PCUs of three smaller state-funded hospitals along the south coast in George (437 km), Port Elisabeth (754 km) and East London, 1087 km to the East of Cape Town.

**CURE** lists 7 Chinese scholars from the Beijing Children's Research Hospital or the Shanghai Children's Hospital who received training in the USA. To enhance language skills CURE developed a CD recording of about 250 medical terms in English with comparable Chinese characters, which is now provided to all selected scholars prior to their training.

**World Child Cancer**, created by ICCCP in 2007, started 6 projects since 2009 to support twinning projects over 5 years with 30'000-40'000 £/year and per project (Malawi, Colombia, The Philippines, Ghana and Mozambique).

**My Child Matters** runs about 20 ongoing projects in 16 countries, and supported about 30 projects previously.

### **Restructuration of the PODC Committee**

In order to increase the efficiency of the PODC Committee, a proposal for a reorganisation of the latter was discussed at the SIOP congress in Vancouver in 2005, accepted, submitted to the Board and published in the December 2005 issue of the SIOP NEWS. By letter of June 24, 2009, the president of SIOP informed the chairman of the Committee that the Board and Council of SIOP had accepted the proposal and requested the formulation of terms of references (TOR). The main ideas were to form working groups (WGs: open to all members of SIOP) and a core committee formed by the chairs of the WGs and representatives of the Council. It was proposed that the core committee supervises the WGs, defines parameters to assess the status of the progress of pediatric oncology in different countries, and develops strategies to translate the visions of SIOP. It was also proposed that the core committee elects the chairperson of the PODC Committee.

The date and time of the PODC Committee restructuring meeting was announced in the July/August 2010 issue of the SIOP NEWS and in the program of SIOP 42. Calls for proposals for WGs, members of WGs and chairpersons of WGs were sent out in December 2009, April 2010 and September 2010. Twenty-five different WGs were proposed by 97 SIOP members willing to work in a WG, and 14/97 were also willing to chair a WG.

At the **Restructuration Meeting on October 20, 2010**, the number of WGs was reduced to 12. For each WG 1-4 convenors were nominated. The WG for advocacy and the WG for education and training were linked to the respective task forces, the WG for supportive care and nutrition to SIOP's Supportive Care Group..**On October 21, 2010, the Board and Council approved the new structures and at the first meeting of the new PODC Core Committee on October 22, 2010** the plans for the WGs, taking into account the reduction of WGs from 25 to 12 requiring reattribution of WG members, was discussed and accepted. Most of the newly elected WG convenors accepted to be candidate for the chair of the PODC Committee. **In a secret vote Scott Howard was elected chairman and he chose Trijn Israels as vice chair.**

### **The new WGs and Convenors** were

Graduated intensity treatment guidelines	T, Israels, E. Bouffet
Refusal and abandonment of treatment	R. Ribeiro, R. Arora
Palliative care	A. Shad, J. Margolin
Supportive care and nutrition	P. Rogers, R. Kebudi, M. van de Wetering, T. Lehmebecher
Late effects and survivorship	P. Kurkure
Nursing	R. Hollis, J. Challinor
ICCCPO parent support groups	K. Dollman, B. Pau
Twinning, collaboration and support	M. Harif, T. Eden, G. Veez
Tools for communication, collaboration and clinical research	Y. Quintana, A. Belgaumi, V. Kanwar
Advocacy	M. Kruger, S. MacFarlane
Education and training	R. Dalvi, B. Agarwal
Essential drugs	R. Barr

PODC Chair Emeritus. HP Wagner, PODC Evaluation Officer: A. Veerman.