A Brief History of Pediatric Oncology

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Robert Carachi and Jay L. Grosfeld

Dr Odile Schweisguth was born during the turbulent period of the first world war in Vosges (France) in 1913. Her first contact with medicine was at the Red Cross Nursing School and with the mentoring and support of one of her teachers there, was admitted to the medical school in Nancy in 1932, graduating in Paris in 1936. Her early training was carried out in "Hopital des Enfants Malades" in Paris. She became the first pediatric oncologist when she was appointed to the Consultant post in 1948 at the Institute Gustave Roussy to establish a new paediatric section at this renowned Cancer centre in France. She set up over her working life until she retired in 1978, a separate paediatric oncology ward fully staffed caring for children with cancer and to look after the dying children. The volume of patients increased to 350 per year once it was fully established. Her visit in 1959 for 2 months to the Sidney Farber at the Boston Children's Hospital established a lifelong friendship and a strong voice for children's cancer. Her interest was on long term morbidity because the main treatment modality available at that time was radiation and radiotherapists had no means of scaling down the treatment for children. She was a strong advocate for the rights of childhood cancer survivors. An initial meeting on childhood cancers in 1959 was organised and Odile Schweisguth was its director. This led to comprehensive pediatric oncology care worldwide with the formation of the new society called Societe International d'Oncologie Pediatrique, at a meeting in Madrid in 1969. She was elected as the first Present of SIOP, with a membership worldwide of over a thousand members. Odile died at the age of 89 in March 2002.

About SIOP

History

On 3 July 1967, a small group of paediatricians, surgeons, pathologists and others met in the Paediatric Department "Service Milhit" of the Institut Gustav in Villejuif/Paris, France. Everyone there knew SIOPs now honorary member Dr Odile Schweisguth, and shared a keen interest in paediatric oncology.

A decision was taken at this meeting, to form the Club d'Oncologie Pediatriquie (Paediatric Oncology Club). During the second meeting of the Club, held at IGR in 1668, participants agreed to convene the following year in Madrid, hosted by the late Dr J Monereo, Paediatric Surgeon. It was during this memorable assembly that it became obvious that there was a clear and widespread interest in paediatric oncology and the Club was transformed to the Societe International d'Oncologie Pediatrique (SIOP) on 6 November 1969.

The Founding Members of the Society who were present at the founding meeting of the Society in Madrid and voted for the constitution, were Doctors Bouchon, Boureau, Brunat, Carton, Delemarre, Gerard-Marchant, Gompel, Gubler, Hitzig, Hurtado, Kaser, Lemerle, Massimo, Maurus, Monero, Neidhardt, Noel, Pages, Payan, Pellerin, Pluss, Orsini, Raybaud, Schlienger, Schweisguth, Sullivan, Voute and Wagner. SIOP was initially a bilingual Society; French and English were both used at meetings. According to the statutes, it is still bilingual; however English has taken over as the conference language, but a French flavour remains!

Furthermore, SIOP has fulfilled its original intention of becoming a truly international society and not restricting its influence and membership to one continent or part of a continent. Over the years, most of the annual meetings have been

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R. Carachi, MBE, MD, FRCS, Phd.FEBPS (✉)
Department of Surgical Paediatrics, Yorkhill Hospital,
Glasgow, Scotland, UK
e-mail: Robert.Carachi@glasgow.ac.uk

J.L. Grosfeld, MD, FACS, FAAP, FRCS (✉)
Department of Surgery, Riley Hospital for Children,
Indianapolis, IN, USA
e-mail: jgrosfel@iupui.edu

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held in Europe, the saying "doing Europe with SIOP", but this policy has been changed and at the moment, the majority of our members are from Europe and North America.

In the early years, the Society was mostly clinically orientated, promoting involvement in clinical studies and trials, such as medulloblastoma, neuroblastoma and rhabdomyosarcoma, for example. Eminent surgeons, pathologists, paediatricians and radiotherapists met together. In recent years, more basic scientific aspects of paediatric oncology have featured at the annual meetings.

SIOP continues to work in the interest of our patients, children with cancer, who wish to be cured to lead normal lives alongside other healthy children.

SIOP was legally established in 1969. Under the name of International Society of Paediatric Oncology there exists an association governed by the present statutes and by the provisions of articles 60 ff. of the Swiss Civil Code. Its registered office is in Zurich, Switzerland.

The first annual general meeting was held in Madrid (Spain) in 1969 and was devoted to neuroblastoma, nephroblastoma, lymphoscarcoma and immunology. Beginning with a few enthusiastic members to more than 1400 active Ordinary Members, SIOP remains a friendly Society in which all the challenges of treating patients with malignancies are discussed in depth. The central secretariat of SIOP is established in The Netherlands where one can receive detailed information on the Society. Address of the Secretariat is:

SIOP Secretariat c/o Kenes Associations Worldwide
1 – 3 Rue de Chantepoulet
1211 Geneva, Switzerland
Email: irah@kenes.com

Societe Internationale D'Oncologie Pediatrique- International Society of Paediatric Oncology

Constitution

1. The official name of this organisation shall be the Societe Internationale d'Oncologie Pediatrique with the acronym SIOP. It is also to be known by the English translation; namely the International Society of Paediatric Oncology. The name of the organisation and its acronym SIOP may only be used by a member for professional identification or in a curriculum vitae. A member shall not use the name or acronym for any commercial purpose or to advertise his services without the express approval of the Board. A violation of this prohibition may subject the member to censure, suspension or expulsion from the Society by the Board.

   The Society was founded in 1969. Under the name of "International Society of Paediatric Oncology" there exists an association governed by the present statutes and by the provisions of articles 60 ff. of the Swiss Civil Code.
2. SIOP has its domicile where its administration is domiciled.
3. The financial year starts with the annual Congress of the Society in October each year or as may be decided by the Board.

Article II: Vision and Mission of SIOP and charitable status of the Society

SIOP is a non-profit organisation and acts in a selfless manner. Members do not receive funds or additional benefits. SIOP aims for a charitable tax exempt status.

1. Vision

   No child should die of cancer
2. Mission

   The mission of the international Society of Paediatric Oncology (SIOP) is :
   (a) To ensure that each child and young adult with cancer has access to state of the art treatment and care
   (b) To ensure that all involved in childhood cancer worldwide have access to the latest progress through meetings, networking and continuing professional development
   (c) To support those caring for children and young adults with cancer to provide the best curative and palliative therapies.
   (d) To advocate for appropriate longterm follow up for children and young adults after treatment for cancer.

The International Society of Paediatric Surgical Oncology (IPSO)

IPSO is an international society of surgeons who specialise in the surgical care of children with cancer.
IPSO's aims are:

- To set up a global standard for surgical care of children with cancer
- To provide a forum and enhance communication between surgeons who specialise in children's cancer
- To promote and support clinical trials aimed at improving the outcome in the treatment of children's cancer
- To encourage co-operation with other organisations concerned with children's cancer

IPSO is a truly global organisation with an expanding membership from all parts of the world. At the last count, 48 countries were represented. Membership is open to all surgeons who have a demonstrable commitment to paediatric surgical oncology, and we are always keen to attract new members.

IPSO meets once a year in conjunction with our sister organisation SIOP (The International Society of Paediatric Oncology) and has regular joint meetings with other international organisations who represent specialist children's surgery.

IPSO strongly supports the continuing professional development of surgeons who care for children who have cancer, and to this end IPSO runs an annual course in paediatric surgical oncology, in collaboration with EUPSA (the European Paediatric Surgeons Association).

Historical Background

IPSO

Aims

To:

Further knowledge, promote research and set standards in paediatric surgical oncology :

Facilitate communication between various surgical disciplines (orthopaedics, neurology, plastic surgery etc) and also other medical specialties involved in the treatment of paediatric cancer. Maintain a forum for discussion and/or advice on problems relevant to paediatric surgical oncology.

Exchange and diffuse information on paediatric cancer in general which may impact surgical practice. Be involved in the formulation and implementation of requirements for postgraduate training and education as well as specialist recognition on an international level.

Development

1989: First full surgical symposium back to back with SIOP meeting Prague.
Main topic Surgical Oncology (local organisers J Snadjauf J, Koutecky)
1990: Second surgical symposium back to back with SIOP meeting Rome, 1990. (Local organisers C Boglino, R Cozzi, M Castello)
1991: Letter of intent to form an independent society sent to all participants of above symposia and other pediatric surgeons known or shown to have special interest in surgical oncology. Number 179. (D Hays)
1991: Draft constitution prepared by A Gentil-Martins
1992: Positive response received from 1010 replies (List of names and countries available)

IPSO Officially founded as independent society in 1991 at Rhodes SIOP meeting (Again including a separate surgical symposium Local Organiser – D Keramidas).

Constitution and executive council approved at first general assembly

Membership: All surgeons attending any of the three above symposia considered as members (numbers) see attached list.
Executive 1991
Founding President – J Plaschkes
Secretary/treasurer – R Spicer
F Cattalliotti
A Gentil-Martins
P Exelby (SIOP scientific committee representative)

A Brief History of Modern Pediatric Oncology in the United States

Following WWII, as many medical specialists returned to civilian practice, an increased interest in improving the dismal outcome for children with leukemia and other malignant conditions was observed. Early use of then sparsely available chemotherapy in leukemic children was spearheaded by the work by Sidney Farber in Boston in 1948. Implementation of postoperative radiotherapy for children with Wilms tumor was reported by Gross and Neuhauser in 1949. However, the relatively low incidence of childhood cancer cases managed at any single center made it difficult to determine the most appropriate treatment and stimulated interest in developing collaborative efforts to accrue an adequate number of patients for clinical studies. It soon became obvious that in order to carry out randomized prospective and controlled clinical trials would require cooperative group studies implementing multidisciplinary care including, surgery, radiotherapy and chemotherapy.

In 1955, the Acute Leukemia Cooperative Chemotherapy Study Group A was formed. This was mainly an adult study group that also cared for some children with leukemia. The group's activities expanded somewhat to include patients with solid tumors including cases of Wilms tumor and neuroblastoma. In 1967, childhood cases split off with formation of the Children's Cancer Study Group A (CCSG-A). Subsequently, the name was shortened to the Children's Cancer Group (CCG). In 1968, the National Wilms tumor Study Group (NWTSG) was formed led by Dr. Giulio D'Angio (a radiotherapist). The other founding members included Drs. Daniel Green, Audrey Evans (Hematologist-Oncologists), J. Bruce Beckwith (pathologist), and Norman Breslow (statistician). Drs. Harry Bishop (pediatric surgeon) and Willard Goodwin (urologist) joined the initial group. Since then this highly successful group has carried out a total of five different major Wilms tumor studies leading to an overall survival rate of near 90 %. Full details concerning Wilms tumor are covered in detail in Chap. 12.

During the same period, in 1956 the Southwest Cancer Chemotherapy Study Group (SWOG) was organized with a small pediatric component based at the MD Anderson Cancer Hospital in Houston, TX. In 1973 SWOG merged with the Cancer and Acute Leukemia Group B (CALG-B) which included both adult and pediatric oncologists. In 1979 the pediatric oncologists split off and developed the Pediatric Oncology Group (POG) led by Dr. Teresa Vietti of St Louis, MO.

In 1970 the Intergroup Rhabdomyosarcoma Study Goup (IRSG) was formed with members from both CCG and POG. Dr. Harold Mauer (Hematology-Oncology) was the lead physician supported by Drs. William Newton (pathology), Ruth Heyn, Milton Donaldson (Hematology-Oncology), Daniel Hays and Walter Lawrence (Surgeons) and Melvin Tefft (radiotherapy).

In 2000, The NWTSG, IRSG, CCG and POG merged into a single group named the Children's Oncology Group (COG).

Children's Oncology Group (COG)

The Children's Oncology Group founded in 2000, is the largest Cooperative Cancer group in the world including the United States, Canada, and a number of international sites (Australia, New Zealand, and areas of Europe). COG sites care for more than 90 % of the 13,500 pediatric cancer patients seen in the US annually.

COG is primarily funded by grants from the US National Cancer Institute (NCI) and other granting agencies as well as philanthropic sources through gifts to the COG Foundation.

There are two types of COG centers:

1. COG Phase I consortium consisting of 21 premier pediatric oncology program centers that carry out early clinical cancer trials, and
2. the Community Cancer Oncology Program (CCOP) centers that manage patients in assigned clinical protocols

Two hundred member institutions in COG carry out nearly 100 clinical trials at any given time. The group manages pediatric patients with hematologic malignancies (leukemias and lymphomas), solid tumors (including bone tumors), central nervous system tumors and rare cancers. Approximately 8000 cancer experts work and perform research at COG facilities. In addition to disease specific clinical research, COG members conduct studies in cancer drug development, supportive care, epidemiology, stem cell transplantation, behavioral sciences and survivorship. The group maintains a vigorous long-term follow up outcomes and guidance program that monitors late effects of treatment.

Scientific research collaboration occurs at a world-wide level in areas such as molecular genetics, molecular biology, immunology, proteomics, targeted therapies, antiangiogenesis, cellular proliferation, apoptosis and tumor vaccine development.

Children's Oncologic Surgeons represent one of the key multidisciplinary groups that compose the COG. There is a COG Executive Committee and the Chair of the Surgery Discipline Committee is the surgical representative to that Committee. When COG was initially formed in 2000, Dr. Gregory Reaman (National Children's Hospital, Washington, DC) was the overall COG Chairman and Dr.

Robert Shamberger of Boston, MA (Boston Children's Hospital) was the first Chair of the Surgery Discipline committee. Dr. Peter Adamson of Philadelphia, PA (CHOP) is the current COG Chairman and the Chair of the COG Surgery Discipline Committee is Dr Michael LaQuaglia of (Memorial Sloan-Kettering Cancer Center), New York, NY. Within the Surgical Committee there is a surgical leadership Group whose members are often appointed to the various solid tumor Committees and other relevant Committees in COG by the Chair. Some examples include:

Neuroblastoma: Dr Jed Nuchtern (Houston, TX) Vice-Chair, and others that are members of the senior surgery investigator group including Drs. Michael LaQuaglia, Andrew Davidoff, Daniel vonAllmen and Stanton Adkins.

Rhabdomyosarcoma: Dr. David Rodeberg (Vice-Chair), Dr. Andrea Hayes-Jordan-other soft tissue sarcomas.

Wilms Tumor: Dr. Peter Ehrlich (Vice-Chair), with Drs. Robert Shamberger, Thomas Hamilton and Michael Richey – senior surgery investigators.

Rare tumors:

- **Hepatoblastoma**: Dr. Rebecka Meyers lead investigator, Drs Max Langham and Gregory Tijan – senior investigators
- **Germ Cell Tumors**: Drs. Frederick J. Rescorla and Deborah F. Billmire Co-Principle investigators
- **Adrenocortical tumors**: Drs. Michael LaQuaglia and Christopher Weldon-Co-Principle investigators

Informatics: Dr. John Doski

Many of the aforementioned individuals are contributors to this 3rd edition of *Surgery of Childhood tumors*.

COG leadership and Operations Center	**COG Operations Center**
Group Chair's Office Peter C. Adamson, MD The Children's Hospital of Philadelphia 3501 Civic Center Blvd, CTRB 10060 Philadelphia, PA 19104 Tel: (215) 590-6359; Fax: (215) 590-7544 Email: adamson@email.chop.edu	222 E. Huntington Drive, Suite 100 Monrovia, CA 91016 Tel: (626) 447-0064; Fax: (626) 445-4334

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