

International Society for Paediatric Oncology

Objectives and Goals 2014-2016

The SIOP Executive Board, 2014-2016

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Executive Summary

The SIOP Executive Board elaborated these objectives and goals for its 3 years mandate. The rational and specific actions are outlined in the document.

Objectives and Goals 2014-2016

Developmental goals

- > To advocate globally for children with cancer and their families
- > To promote the participation of young professionals to SIOP activities and to encourage them to become members
- > To improve SIOP visibility and improve internal and external communications
- To focus attention on future needs of research in pediatric oncology
- To explore possible partnerships with sister societies sharing the same mission and vision and elaborate a common agenda
- > To increase the SIOP membership to have a vibrant society which understands and fulfils the needs of its members

The Internal Actions - 2014-2016

- > To refine the present structure of SIOP
- To write the SIOP Standard Operative Procedure (SOPs)
- > To acquire an electronic repository of all the pertinent documents produced by SIOP for easy access
- To develop "the policy registry"
- To define the present SIOP policy for investing and spending money (GR to report)
- To develop standardized and summarized reports of the Annual Meeting;
- To describe the procedures and responsibilities of the local organising committee and the PCO (Kenes) in order to organize and conduct the Annual Meetings,
- To prepare a three-year report regarding the relationship between SIOP and the present PCO (Kenes);

Section 1: Introduction

This document describes the "Objectives and Goals" that the current SIOP Executive Board Members have decided to pursue during their three-year mandate - 2014-2016 -. The rationale for writing this document is to inform all SIOP members the line of direction which has been decided and to have a reference document to use as a guide for choices and decisions by the SIOP Board. This document and, in particular, the summary report which will be produced at the end of this period, should help to define a continuous pathway and efficient growth strategy for SIOP.

Section 2: Background

SIOP is a robust society in solid financial standing. It is the only international society specific to paediatric oncology. SIOP was founded in the late 1960's. It has grown into a dynamic and vibrant global organisation, with over 1,000 active members worldwide including doctors, nurses, other health-care professionals, scientists and other researchers.

Vision

SIOP's vision is that no child should die of cancer and that survivors of childhood cancer experience the best quality of life possible.

Mission

The mission of the International Society of Paediatric Oncology (SIOP) is:

- To ensure that each child and young adult with cancer has access to state of the art treatment and care.
- To ensure that all professionals involved in childhood cancer worldwide have access to the latest progress through meetings, networking, and continuing professional development.
- To support those caring for children and young adults with cancer and to provide them with the best curative and palliative therapies.
- To advocate appropriate long-term follow up for children and young adults after cancer treatment.

Other considerations

SIOP during its long history has acquired the status of being 'the voice for all children with cancer and their families in the world'. Thus, SIOP has decided to pursue an active and effective advocacy role in addition to being a Scientific Society, committed to enhancing knowledge, innovative ideas, and education while creating networking opportunities among all stakeholders sharing the SIOP vision.

The field of Paediatric Oncology has experienced tremendous progress in the last decades yet access to progress is not equitable across the world. Professionals are spread over the world with an increasing need to be connected and to share and exchange knowledge and the need for large-scale concerted actions has become increasingly evident to us all, as well as the need to guarantee that progress is appropriately accessible to professionals and patients in all countries of the world. All these elements require SIOP to remain a vigorous, a dynamic society capable of adapting itself to this changing world and of embracing new emerging challenges.

Section 3: Preliminary work

Before defining precise "Objectives and Goals", an analysis of the "Context" in which SIOP is operating as well as of the "Strength, Weakness, Opportunities and Threats" – SWOT Analysis – of SIOP was conducted. The results of those two analyses are reported in the following tables.

3.1 Analysis of the context in which SIOP is operating

Trend	Description of the trend	Impact
Financial/ Economic	 Global crisis impacting health-care systems Competitive donor and sponsor environment Cost of membership. Low and Lower-Middle Income Countries constraints 	 Health care professionals in Low and Lower-Middle Income Countries require special support and education. Wide dispersal of specialists within lower income countries
Research	 Lack of access to new drugs in development for paediatric oncology and paucity of major advances in disease management in the most recent years. Competition with international disease-specific groups. 	 Lack of 'breaking news' for SIOP congress Difficult to find sponsorship for Congress and other activities
Education	Continuous need for education.	 Use of social media and online platforms to reach young professionals
Technology	 New technology developing rapidly. 	 SIOP should reconsider the methods it uses to communicate with members.
Politics	 WHO – World health agenda Influence of patient/ parent advocacy networks. Partnering with other societies and organization 	 SIOP needs to be a strong voice for paediatric oncology to ensure it is prioritized on the World Health Agenda Develop MoU with other organizations

3.2 SWOT analysis of SIOP

Strength	Weakness
Only international society for paediatric oncology	Trying to be all things to everyone
Established society with scientific credibility	Focus on congress
Broad scope:	Lack of control of SIOP brand
 clinical knowledge and applicability 	Not using new technology to communicate widely
 diversity of members background 	enough
 Multidisciplinary (Nurses, Medical, Parents) 	Lack of member benefits
 Resources from countries 	Aging society
 Partnering rich/developing countries 	Lack of membership in regions such as North
Strong brand in developing countries	America
Access to leaders in the field	No research leadership of SIOP
Strong leadership	Absent research agenda and confusion with
Strong congress	research mission of SIOPE.
Committed membership	
PODC network	
Opportunities	Threats
Education (early education & experienced)	Economic instability
Global position	Aging population
Partnerships	Development of generic drugs
International exchange	Disease-specific societies and meetings
Enhanced communication & Advocacy	Rising healthcare costs
Point of reference for paediatric oncology	Access to information
Political influence	Focus on other disease areas
Need for global research : smaller subgroups of	Diseases oriented focused meetings
diseases, pathways rather than disease oriented	Cancer in LMIC becoming a competitive area for
research	HIC investigators and institutions.
Reinforce the role of the Young investigators	

Section 4: "Objectives and Goals"

The "Objectives and Goals" which will be herein presented are clustered into two groups. The first one lists a series of actions directed to pursue the missions of SIOP; those actions have been called "SIOP Developmental Goals – 2014-2016". The second one indicates some activities directed to improve and standardized the procedures of the Society; they have been called "Internal Actions". As this document is presented one year into the term of the current SIOP Executive Board, each SIOP Development Goal below includes "actions already taken" and "actions under consideration" or which still need to be taken as well as "internal" goals.

4.1 - The SIOP development goals – 2014-2016

4.1.1 To advocate globally for children with cancer and their families

Actions already taken:

- An ad hoc SIOP Advocacy Committee has been constituted; Dr. Gabriele Calaminus has been appointed as the first chair;
- The terms of reference for this committee have been established1;
- The position paper outlining the SIOP Advocacy role and function has been developed¹;
- The three-year working plan has been developed, highlighting also specific deliverables¹.

Actions under consideration:

- Preparation of position papers on key Advocacy issues (such as access to care, early diagnosis and detection, pain and palliative care, continuity of care, awareness about childhood cancer);
 By pursuing the above actions SIOP will strive to facilitate I) the introduction of "childhood and adolescent cancer" onto the Global Health Agenda in particular the global NCD agenda II)
 Application for official status as a non-governmental organization in official relations with WHO;
- Exploration of partnerships to expand the impact of advocacy.

Financial support:

• To implement all the actions listed above, during the first year of its activity, this committee has been provided with 85'000 Euro, coming from the SIOP reserve budget.

1 All these documents are available on the SIOP website

4.1.2 To promote the participation of young professionals in SIOP activities and to encourage them to become members

Actions already taken:

- The SIOP Scientific Committee has been appointed to pursue this Developmental Goal;
- The "young Investigator" (YI)² awards have been initiated;
- To implement these YI award it has been decided: I) to have a dedicated "YI session" at the SIOP Annual meeting, II) to possibly, create a "YI" working group"; III) to grant the YI winners free SIOP membership for one year and to invite them to participate in the young SIOP group; IV) to offer them specific privileges during the annual meeting (i.e. access to young VIP room); V) to promote the "YI awards" through the PBC journal, through fellowships programs and through major institutions in the world;

Actions under consideration

 To identify the career development needs of young professionals and their expectations by designing a survey;

Financial support:

 An annual budget of 14,000.00 Euros will be allocated to implement this action (derived from the SIOP operational budget) in order to award 14 young investigators with funds for their research activities. These awards will be made at every annual meeting. $\underline{2}$ The Young Investigator award is a prize given to the 14 best contributions presented at the annual SIOP Congress by an investigator younger than 40 years. The winners are selected by the SIOP Scientific Committee.

4.1.3 To improve SIOP visibility and improve internal and external communications

Actions already taken:

• An ad hoc Website and Communications Committee has been constituted; Dr. Paul Rogers has been appointed as the first chair;

Actions under considerations

- To write the terms of reference for this committee;
- To implement Social Media activity for the society;
- To develop an interactive forum on the website;
- To improve the educational content on the website;
- To promote the society activities and the congress with e.g. promotional booths or material at continental meetings and other relevant congresses (ECO, COG);
- To consider monthly article reviews published on the website;
- To send regular society updates (Advocacy, success stories, webcast);
- To establish a communication working group;
- To improve linkages with other websites;

Financial support

• 5,000.00 Euro and 15,000.00 Euros have been allocated respectively for "SIOP promotion and website cost" (derived from the SIOP Annual revenues).

4.1.4 To focus attention on future needs of research in paediatric oncology

Actions already taken:

• The SIOP Scientific Committee has been delegated to pursue this Developmental goal;

Actions under considerations:

- to initiate position papers;
- to hold ad hoc seminars during the annual meeting;
- to promote specific events possibly with industry partners;
- to promote and communicate with scientific leaders and other research organisations worldwide.

4.1.5 To explore possible partnerships with sister societies sharing the same mission and vision and elaborate a common agenda

Actions already taken:

 During the SIOP 2014 congress, business meetings have been organized with IPSO, PROS, POEMS, ICCCPO, WCC, and UICC to address this issue and/or start action.

Actions under consideration

• To be elaborated: a "Memorandum-of-understanding (MoU)" will be used to formalize these possible relationships.

<u>3</u> A MoU between SIOP and ICCCPO has already been signed in 2012 in Hong Kong during the Annual Meeting

4.1.6 To increase SIOP membership and to have a vibrant society which understands and fulfils the needs of its members

Actions to be developed

4.2 The Internal Actions – 2014-2016

4.2.1 To refine the present structure of SIOP

- ➤ Objective To define the present operative structure of SIOP, defining the terms of reference for each committee and each working group as well as reporting mechanisms
- > Responsibilities Paul Rogers, Giorgio Perilongo & Kenes Office
- > Deliverable and deadline conclusive document by December 2014

4.2.2 To write the SIOP Standard Operative Procedure (SOPs)

- ➤ Objective To complete the SOPs according to which SIOP operates
- Responsibilities Giorgio Perilongo & Kenes Office
- ➤ Deliverable and deadline All SOPs written by December 2015
- Possible future action: to look into ISO 9000 feasibility

4.2.3 To acquire an electronic repository of all the pertinent documents produced by SIOP for easy access

- ➤ Objective To make available to SIOP an electronic repository of all pertinent documents
- ➤ Responsibility Kenes Office
- Action after January 2015
- ➤ By September 2016 electronic document repository completed
- > Budget needed to achieve this objective to be evaluated

4.2.4 To develop "the policy registry"

- Objective To record in an ad-hoc elaborated document all the main strategic policy decisions taken by the Executive Board, expected to influence the way SIOP is operating, with a specific review date for each entry.
- Rationale: to leave an evident trace of the main strategic policy decisions that the various SIOP Executive Boards will take in the course of the years for future reference.
- Responsibility Giorgio Perilongo & Kenes Office
- Action to be started at the Toronto congress including actions already taken between 2012 and 2014

4.2.5 To define the present SIOP policy for investing and spending money

- ➤ Objective To document "policy" defining how SIOP manages and uses its reserve money (e.g. investments, expenditures and so on)³
- Responsibility Gregory Reaman
- ➤ Deadline September 2014
- Document see SIOP Budget

<u>3</u> Decisions already taken: I) SIOP will not form a Foundation; II) will not initiate active fundraising campaigns, advocacy actions excluded.

4.2.6 To develop standardized and summarized reports of the Annual Meeting

- Objective to elaborate a summary report of each SIOP Annual meeting with objective quantitative and qualitative data allowing comparative analysis with subsequent meetings and the setting of objectives for future meetings
- Responsibility François Doz, Giorgio Perilongo & Kenes
- ➤ Actions Report available: from the "Hong-Kong meeting" onwards

4.2.7 To describe the procedures and responsibilities of the local organising committee, the scientific committee and the PCO (Kenes) in order to organize and conduct the Annual Meetings, e.g. responsibilities and guidelines for sponsorship

- > Responsibility Perry Gil-Ran & SIOP Executive Board
- > Actions Perry Gil-Ran
- > By September 2014 Document ready to be presented and signed by the chair of the 2015 meeting

4.2.8 To prepare a three-year report regarding the relationship between SIOP and the present PCO (Kenes)

- ➤ Rationale To elaborate a document providing suggestions to the future SIOP Executive Board regarding the renewal or the recession of the contract with Kenes (official date of the end of the contract 31.12.2018)
- Responsibility Giorgio Perilongo & the entire SIOP Executive Board
- Actions yearly reports (as of December of each year of the three-year mandate) and final report by the date of the 2016 SIOP Annual General Assembly

Section 5: SIOP legacy (2014-2016)

To make SIOP:

- A progressively more modern and efficient Scientific International Society capable of accomplishing its mission;
- ➤ A society capable:
 - of influencing the worldwide health agenda with a higher priority for children & adolescents with cancer and their families;
 - of attracting young investigators who want to devote their career to the field of Paediatric Oncology;
 - of expanding its voice within the international paediatric oncology and medical community;
 - of promoting and facilitating research on a global level;
 - of offering opportunities for high level continuous medical education for paediatric and adolescent oncologists;
 - of motivating and recognizing the volunteers and supporting societies;
 - of grooming and mentoring the next generation of leaders.