

Terms of Reference SIOP Advocacy Committee

Background

Advocacy is central for advancing the vision of the International Society of Paediatric Oncology (SIOP): **No child should die of cancer: cure for more, care for all.** Through advocacy, SIOP strives to integrate the needs of children and adolescents with cancer, parents, and survivors into relevant policies and programmes at all governance levels. These efforts are implemented by channelling expertise and raising awareness among decision-makers and interest groups worldwide.

Advocacy activities are either driven directly by SIOP, often in cooperation with partner stakeholders, or framed by organised collaborations. The latter include SIOP's milestone cooperation with the World Health Organisation (WHO) as official WHO Non-State Actor (NSA) and the participation in the WHO Global initiative for Childhood Cancer (GICC). SIOP-driven advocacy activities are synergic and/or complementary to major framework collaborations and include mobilisation around annual campaigns such as Gold September – Childhood Cancer Awareness Month, the International Childhood Cancer Awareness Day, and others.

Advocacy is prominent in SIOP's Strategy 2021 – 2025 under **Goal 2: Advocating Globally for Children and Adolescents with Cancer.** The three focus areas and indication of pursued outcomes are summarised below.

1. Development and sharing of advocacy & technical expertise to improve childhood cancer services

- Contributions to Technical Guidance developed by relevant WHO partnerships including GICC
- Inclusion of Childhood Cancer in other relevant areas of WHO work, e.g. COVID-19 response, Non-Communicable Diseases and Child Health more generally

2. Promotion of enabling policies and arguments for resource allocation to childhood cancer

- Recognition of Childhood Cancer as a treatable and potentially curable child health care need
- Meaningful inclusion of Childhood Cancers in National Cancer Control Plans (NCCPs)
- Coverage of childhood cancers by Universal Health Care schemes
- Timely and affordable access to chemotherapy and supportive Essential Medicines (e.g. WHO EMLc)
- Informed members' action across global settings, e.g. underpinned by an Advocacy Toolkit, SIOP Congress policy sessions

3. International commitments to childhood cancers and SIOP's visibility

- Impactful own policy events and speaker contributions to strategically relevant external meetings, e.g. WHA side-events, country workshops
- Advocacy publications on topical issues (journal commentary, position papers/ letters)
- Profiling of Childhood Cancer in strategically relevant third-party statements (e.g. UICC)
- Strategic stakeholder mapping and novel collaborations

- Widely profiled international campaigns: Gold September, International Childhood Cancer Day, adolescents and young adults, survivorship in LMICs, etc.

The SIOP Advocacy Committee

Role

The SIOP Advocacy Committee provides strategic direction in line with Goal 2 of SIOP's Strategy 2021-2025 and oversees the implementation of targeted activities together with the SIOP Board of Directors. It is supported by the SIOP-SIOPE Senior Policy Officer and works closely with the SIOP Secretariat.

Composition

The Advocacy Committee is composed of SIOP members with a track record of impactful engagement in cross-border policy and campaigning on Childhood Cancer.

The Committee membership reflects the global multi-disciplinary nature of the broader SIOP community. The number of members enables the Committee to operate efficiently in its dynamic environment.

Nomination & Appointment

- The process to constitute the Advocacy Committee is organised through a formal call for nominations organized by the SIOP Secretariat on behalf of the SIOP Board of Directors (BoD)
- BoD members can either volunteer to be part of the Committee or propose one representative from their respective regional or disciplinary constituents
- Any SIOP member can self-nominate themselves following the instructions in the formal call for nominations
- Committee members are selected from the pool of submitted nominations by the SIOP President, Past President, and Secretary General
- Committee Members are formally appointed by a communication from the SIOP President
- SIOP President and Past President can independently elect to be part of the Advocacy Committee
- An open invitation to contribute to the Committee deliberations is furthermore extended to SIOP members with official roles in key framework partnerships as defined by the BoD (e.g. WHO Global Initiative for Childhood Cancer, UICC, NCD Child)

All Advocacy Committee members are expected to be SIOP members in good standing.

Duration of mandate

Committee members are elected for three (3) years in the first instance. Their mandate can be renewed once for a total maximum duration of six (6) years. The renewal of the mandates, or further nominations should a Committee member choose to step down, take place in consultation with the SIOP BoD.

Expected time commitment

Advocacy Committee members are expected to work on advocacy tasks on average 1 hour/week. The Chair of the Advocacy Committee is expected to work on and lead the advocacy initiatives on average 2 hour/week. The time commitment for the months of February and September is higher because of global advocacy campaigns on childhood cancer.

Chair

The Chair ensures that the Committee contributes effectively to the agenda laid out in SIOF's Strategic Goal 2 – Advocacy and facilitates the advancement towards the objectives set by the Committee. The Chair reports on activities to the SIOF BoD on a quarterly basis. If not already a member of the SIOF BoD, the Chair has a position on the BoD in accordance with the SIOF Constitution. The Chair is appointed through an open call to the membership for expressions of interest and decided upon by the President in consultation with the SIOF BoD. The term of the Chair's mandate is set to 3 years. To ensure continuity, a Chair-elect is appointed in the 2nd year following the same process.

Decision-making

Decisions are taken by majority (50% of the Committee + 1). If there is an equal number of votes, the Chair will make the final decision.

Conflict of interest

Committee members will declare any conflicts of interest (or potential conflicts of interest) with relevance to the advocacy mandate (e.g. affiliations with (or investments in) pharmaceutical industry, official positions for-profit organizations engaged in business with SIOF or in non-profit organizations in formal partnership with SIOF).

Terms of Reference

- Identify opportunities and facilitate contributions to shape childhood cancer service organisation and delivery (such as through (inter)governmental or other internationally recognised multi-stakeholder channels including WHO Global Initiative for Childhood Cancer)
- Foster the position of SIOF as the go-to scientific interlocutor of the WHO and other global health stakeholders on all issues pertaining to childhood cancers
- Strengthen the position of SIOF as a key interlocutor of the WHO and other global health stakeholders on child and adolescent health and overarching oncology topics
- Support the SIOF continental branches in regional advocacy initiatives, e.g., high-level public health summits, lobbying national governments to integrate childhood cancer treatment, care and support into their health systems.
- Integrate childhood cancer perspectives into relevant high-agenda topics in global health policy (e.g. COVID-19)
- Foster strategic links and opportunities for advocacy at the regional and national levels in relevant areas (health, children and youth affairs), incl. dialogue with WHO regional headquarters and other UN agency representations
- Provide strategic direction to the annual advocacy and awareness campaigns
- Ensure that the voice of parents, patients and survivors is represented through partnership with Childhood Cancer International (CCI)

- ‘Open doors’ and facilitate strategic engagement with decision-makers, opinion leaders, and key interest groups including media at all levels
- Guide content development for SIOB policy and advocacy publications, both internal and external, and provide strategic direction to their dissemination
- Lead the development of the SIOB Advocacy Toolkit to support members’ efforts at all levels – including defining key messages, target interlocutors, and channels of engagement
- Contribute to policy-related sessions at the SIOB Congress
- Participate in meetings with the WHO and other global health policy stakeholders
- Participate in regular Advocacy Committee coordination calls
- Meet face-to-face at least once a year (i.e., during SIOB international annual conference) to move SIOB agenda forward.

SIOB Office Advocacy Support

The tasks of the Advocacy Committee will be supported by the SIOB-SIOPE Senior Policy Officer in close collaboration with the SIOB Secretariat.