**S I O P E N**

**Association to foster Neuroblastoma Research**

**( S I O P E u r o p e N e u r o b l a s t o m a G r o u p )**

**S t a t u t e s o f t h e A s s o c i a t i o n**

**§ 1 Name, registered office and sphere of activity**

1. Under the name “SIOPEN” an Association to foster Neuroblastoma Research with legal capacity in terms of art. 1 Austrian Association Law 2002 (VereinsG 2002) is established (hereinafter referred to as “Association”). SIOPEN represents an Association to foster Neuroblastoma Research (SIOPEN Verein zur Förderung der Neuroblastomforschung).
2. The Association is registered with the competent register of Associations (ZVR-number 396592912). The registered office is located in 1090 Vienna, Zimmermannplatz 10.
3. The duration of the Association shall be indefinite and shall be governed by Austrian Law.
4. The Association is a non-profit organisation and is not for profit in all concerns according to the § 34ff Austrian Federal Tax Code (Bundesabgabenordnung – BAO). The Association pursues no economic interest for its own benefits.
5. Its activities will cover countries in Europe and other non-European associated member countries.
6. English will be the working language of the Association. The Statutes will be translated into English.

**§ 2 Purpose of the Association**

**(1)** The purpose of the Association is to perform and facilitate clinical, translational and basic research for children and adolescents with neuroblastoma in European countries as well as worldwide in order to improve the outcome of these patients.

**(2)** The specific aims to fulfil the purpose of the Association are as follows:

1. To perform scientific research projects;
2. To promote and support international collaborative clinical trials;
3. To promote and support collaborative basic and translational research through the European Neuroblastoma Research Network and complementary infrastructures in individual countries;
4. To promote the pooling of data, imaging and biological material to facilitate the development of harmonised standards, procedures, methodologies, processes or common research instruments and to design and implement improved risk-adapted clinical trials. The development of virtual or physically centralized tissue banks across member countries is essential to this aim;
5. To develop communication tools, database platforms and other applications to promote communication among clinical and research institutions, universities, associations and charities involved in neuroblastoma in Europe and internationally. This will facilitate professional medical, nursing, scientific and educational co-operation and training throughout Europe and internationally;
6. To promote the development of European and international guidelines and standards relating to diagnosis, treatment, monitoring, patient care and staff training in order to improve the care of patients with neuroblastoma;
7. No person shall receive benefits that are not directly connected to the aims of the Association or receive unreasonable payment from the Association;
8. The purpose of the Association shall be achieved by means of the following tasks and activities: e.g. collaboration in research, working groups, forums, charities, development of scientific and public networks, development of databases and virtual communities, collaboration with journals, preparation of publications and studies, international cooperation and collaboration relating to meetings, congresses, talks, workshops and scientific documentation. This includes the installation of a website and other electronic media;
9. In pursuit of these goals and objectives the Association may conduct, operate, coordinate, participate in and support charitable and other publicly beneficial programmes and activities, whether they are programmed activities of the Association or of other natural persons and/or legal entities that the Executive Committee may deem constructive and appropriate;
10. The Association may exercise the right of ownership or possession of office premises, property and assets, both material and immaterial assets and shall use them for the exclusive purpose of advancing the Association’s goals and objectives, as described here and before;
11. The Association may carry on business or other activities that refer to the foregoing purposes and support the objectives of the Association;
12. The Association may conduct any other activities that may be necessary, useful or desirable for the support or accomplishment of the objectives, provided that those activities would not endanger the Association’s charitable or tax-exempt status. In particular, also other non-profit organisations with the same purpose (clinical, translational and basic research for children and adolescents with cancer) may be supported in terms of SIOPEN projects;
13. Establishment of and shareholding in capital companies that support the purpose of the Association;
14. The activities of the Association will be carried out without any purpose of seeking a material gain for its Members. Any income, profits or other payments to the Association will be used to promote the goals of the Association and finally all of its members and collaborators.

**§ 3 Means for achieving the purpose of the Association**

**(1)** All resources and means of the Association may be used exclusively in accordance with the Statutes of the Association.

**(2)** To achieve the purpose of the association, the Association may use all means mentioned below that contribute directly or indirectly to these objectives.

**(3)** The necessary material means will be raised through the following:

1. Funds, donations, collections and subsidies from public authorities and private parties; subsidies of the European Union and other organisations.
2. Performance of studies
3. Proceeds from reference services/diagnoses within industrial cooperations
4. Royalties and proceeds from patents
5. Proceeds from promotions and events
6. Individual membership fees and membership fees of the member countries/centres
7. Proceeds from consulting services and courses
8. Sponsoring funds and advertising revenue
9. Inheritances and other contributions
10. Interest income
11. Proceeds from scientific publications
12. Other contributions.

**§ 4 Individual Membership**

1. **Full Members (FM)** shall be physicians, scientists or other healthcare professionals regularly attending SIOPEN meetings fully taking part in and contributing to the work and activities of the Association. All FMs have voting rights and may become members of the Board
	1. **Founding Members** are physicians/scientists of the SIOPEN group already active and involved with the group’s aims and cooperative work prior to October 2008. They confirmed their will to become **Full Members** of the Association by supplying their curriculum vitae.
2. **Full Members:** thoseindividualswishing to become members after January 2009 need to apply online. They will be ratified by both the Executive Committee and the hitherto existing Full Members at the Annual General Meeting. The list of proposed new members will be circulated at least two weeks before the annual meeting of the Association.
3. **Associate Members:** these are members who wish to be associated with SIOPEN.
	1. Under the present Statutes this category applies to natural persons and company representatives that support the activities and the purpose of the SIOPEN Association according to Statutes.
4. In particular, this applies also to natural persons and representatives of parent associations as well as charities and similar organisations that support the activities and the purpose of the SIOPEN Association according to Statutes
5. Also persons (clinicians and scientists) from countries outside the SIOPEN network can be accepted as associate members.
6. Trainees are welcome at all open meetings and can be associate members. They can become Full Members once they are in a substantive post.
7. Associate members will not have the right to vote.
8. **Honorary Members** are persons who have been nominated as such due to their extraordinary merits for the Association and will be elected by the Executive Committee. Honorary members will not have the right to vote.
9. **Provisional members** are prospective new members. They can apply online via the website and will become provisional members in the first instance allowing them to register for meetings. Provisional members will not have the right to vote.
10. **Membership Process**
	1. All applications for membership will be made online at www.siopen.org.
11. Applications for **Full Membership** after 2008 need to be supported by the National Representative. Applications must be accompanied by a curriculum vitae of the candidates.
12. The suggestions for **Associate Membership** shall be made by a FM of the Board. The FMs acting as patron will hand in the applications in written form summarising the specific background of the individual or organisation and include the curriculum vitae of any applicant.
13. The suggestions for **Honorary Membership** shall be made by a FM of the Board. The applications should be in writing summarising the specific merits including the curriculum vitae of the candidate. The candidate will need to confirm if he/she is willing to stand.
14. After having submitted their curriculum vitae and the approval of the National Representative of the respective country, provisional members can apply for becoming Full or Associate members.
15. The Executive Committee will communicate approved applications for the respective category of membership on the occasion of the Annual Meeting. Full Members may only vote the following year.

**§ 5 Individual members’ rights and duties**

1. All members are entitled to take part in the Annual and Spring Meetings of the SIOPEN Association and General Assembly.
2. Voting rights
	1. At the General Assembly the Association’s Full voting Members shall consist of at least three individuals who shall be established in accordance with the laws and customs of their countries of origin.
3. The right to vote in the General Assembly, the Board and the Executive Committee is stipulated in § 9.
4. For all SIOPEN functions remote voting (e.g. electronically) is permitted, provided the validity of the procedure can be assured and appropriate timelines and procedures are followed as detailed in § 9.
5. Further rights of Full Members:
	1. To be elected as a member of a study or specialty committee of the Association.
6. To request a copy of the Statutes of the Association from the Executive Committee
7. To receive information from the Executive Committee about the activities and financial status of the Association.
8. As a group comprising a minimum of one tenth of the Full Members, may require the Executive Committee to call an extraordinary General Assembly or to report on the activities and financial status of the Association within four weeks.
9. To advance an opinion, to make applications and to participate in discussions in each General Assembly or other open meeting.
10. Duties of all members:
	* 1. All members are obliged to promote the interests of the Association and to refrain from actions that could adversely affect the reputation or purposes of the Association.
		2. All members should comply with the articles of these Statutes and the decisions of the representative bodies of the Association.
		3. In case of nominations to a specific function within the SIOPEN Association FM need to confirm that they are willing to stand (or declare themselves as not available) and provide the SIOPEN community with their Curriculum Vitae and a motivation letter.

**§ 6 Termination of individual membership**

**(1)** The membership terminates on death, voluntary resignation or expulsion.

**(2)** Voluntary resignation may occur at the end of each quarter of each calendar year and is made through written notification to the Executive Committee not later than four weeks prior to the resignation date. If the announcement is delivered too late, it is effective at the next withdrawal date.

**(3)** All provisional members who have not been confirmed as Full or Associate Members at the next responsible General Assembly will be removed from the membership list at www.siopen.org.

In extraordinary circumstances the expulsion of a member can be decided by the Executive Committee. This needs to be ratified by a simple majority vote of the Board following a full report and after the member has been given the opportunity to fully present the arguments in his/her favour.

**a)** Circumstances that may lead to expulsion of a member include:

* + 1. Gross infringement of the Statutes
		2. Dishonourable behaviour within the Association

**b)** Following the decision by the Executive Committee and ratified by the Board to expel a member, they shall have one month to appeal that decision. Such an appeal shall be made in writing to the Executive Committee and will be decided by simple majority vote at the next General Assembly. Until this decision the membership is suspended.

**§ 7 Country/Centre Membership**

1. Institutions wishing to participate in SIOPEN clinical trials will require prior approval from the SIOPEN Board. In some circumstances, such as where there is a national childhood cancer organisation, approval may be granted to a whole country rather than individual centres. Following such approval, individual centres (hospitals or institutions) or countries as a whole will be considered as SIOPEN Member Centres or Member Countries.
2. Such membership is distinct from individual membership as a Full, Associate or Honorary member and one does not necessarily imply the other; i.e. SIOPEN individual members do not have to work at a SIOPEN Member Centre and working at a SIOPEN Member Centre or in a SIOPEN Country does not automatically convey SIOPEN individual membership.
3. The process determining approval of Member Centres/Countries shall be decided by the Executive Committee. The Executive Committee will nominate a patron for new countries applying to become a SIOPEN Member Centre/Country. The Board will ultimately approve them to become a full SIOPEN Member Centre/Country following a successful SIOPEN evaluation procedure. Some countries may require a one year observation period. Evaluation and site visits of a candidate Member Country will ideally be undertaken by an active or ex- Member of the Executive Committee or a Specialty Committee chair.
4. To cover the costs of trial management, Member Centres/Countries will be expected to make an annual financial contribution to SIOPEN as proposed by the treasurer and budgeted by the SIOPEN Board (membership fee of the membership countries/centres).
5. In the event of persistent failure of Member Centres/Countries (continuing more than 24 months) to make such a financial contribution and after two written reminders a decision by the Executive Committee will need to be taken. It is clear that for the stability and wellbeing of the group there cannot be major discrepancies between Member Centres/Counties. Exclusion of a Member Centre/Country from SIOPEN trial participation may follow the decision by the Executive Committee. This decision would need to be ratified by the Board. After this ratification, the National Representative(s) of that centre/country will have one month to appeal the decision. Such an appeal shall be made in writing to the Executive Committee and will be decided by simple majority vote at the next General Assembly. Until this decision SIOPEN clinical trial participation from the country/centre will be suspended.

**§ 8 Bodies of the Association**

**(1)** The bodies of the Association are as follows:

1. **General Assembly** comprising all Individual Members of the Association. Only Full Members may vote.
2. **The Board** consists of Full Members carrying specific functions within SIOPEN and shall include:
3. One National Representative from each approved Member Country/Centre (see § 9, section 2 for details);
4. SIOPEN Clinical Study Chairs;
5. SIOPEN Specialty Committees Chairs;
6. All past and present Executive Committee Members;
7. All past Presidents.

In advisory capacity the Board can call in delegates representing supporting Charities or parents’ associations. Their role is further described in §11.

The Board is approved by the General Assembly and engaged to lead and direct all SIOPEN affairs on behalf of the General Assembly.

1. **The Executive Committee is the leading management body of the SIOPEN Association (§ 9, section 3).**
2. **Treasurer and accountant/annual auditor (§ 10)**
3. **Court of Arbitration (§ 13)**

**(2) The term of office** within SIOPEN depends on the specific functions within the Association. The term of office for members of the Executive Committee is 4 years and re-election is permitted after at least one term of rest. For the President, the term of office is 2 years, extendable to 4 years. In exceptional circumstances, the EC can propose to extend the president’s term with an additional 2 years. However, the total term should not exceed 6 years. This proposal has to be validated by a majority vote of two-thirds from the full members present at the Annual or Spring SIOPEN Meeting. Full members on the Board are approved by their respective committees at least every four years but may be replaced for specific reasons if necessary or on personal request. New Board Members are to be approved by the General Assembly. [See appendix I relating to one-time interim arrangements agreed in October 2011].

**§9 Functional profile of Bodies of the Association**

1. **The General Assembly**
2. The General Assembly is convened at least every year by the Executive Committee at the SIOPEN Annual General Meeting (AGM). The invitation must include an agenda of the items and all necessary supporting information or documents that should be discussed as well as the place and time of the meeting. Each General Assembly shall be announced to the members in writing by any legal means (including electronic transmission) by the Executive Committee not later than two weeks before the event. A virtual (Web based) General Assembly may alternatively be convened if deemed necessary by the Executive Committee and electronic voting by any means permitted by applicable law, including but not limited to electronic, internet, or email-based alternatives, is accepted as an adequate mean to take necessary decisions in a timely manner. It follows the same rules as outlined above. Voting procedures will be conducted in a manner providing for secrecy of the ballots and allowing one vote per person only.
3. The **Administrative Duties** of the General Assembly at the Annual or Spring SIOPEN Meeting or alternatively in a virtual General Assembly meeting including an electronic voting procedure are approval of:
4. Changes within the Board;
5. Changes within the Executive Committee;
6. Approval of the new members
7. Approval of the annual Activities Report by a Member of the Executive Committee;
8. Decisions on any necessary alterations and/or amendments of the Statutes and of dissolution of the Group.
9. **Responsibilities of the General Assembly**. The following decisions are reserved to the General Assembly of Voting Members:
	1. Accepting and approving the Annual Reportand the closing of accounts (profit and loss account including the statement of assets and liabilities) or annual accounts.
10. Granting of official approval of the Executive Committee, the treasurer and of the accountant/annual auditor for the past term of office
11. Appointing and dismissing the accountant/annual auditor upon proposal of the Executive Committee.
12. Approval of up to three elective members in the Executive Committee in the context of special tasks for the Association. The task and function are validated and re-evaluated each year. The re-appointment is made at the General Assembly.
13. Approval of the elected Executive Committee Representative of the five large countries and of the elected **Executive Committee Representatives** of the remaining countries
14. Decision-making on any necessary alterations of these **Statutes**
15. Decision-making on dissolving the **Association**
16. The General Assembly has all such powers that are transferred to another body of the Association under the present Statutes. The General Assembly delegates managing powers to other bodies of the Association in particular to the Board and the Executive Committee.

The General Assembly empowers the Board to take actions and decisions that are necessary throughout the year with respect to specific clinical and research tasks.

The General Assembly empowers the Executive Committee to manage the daily business of SIOPEN tasks as defined under (§9) and to take ultimate vital decisions for the good and on behalf of the SIOPEN Association whenever necessary.

**e)** Requests to the General Assembly shall be submitted to the Executive Committee in writing at least two weeks prior to the date set.

**f)** The General Assembly has a quorum if all members have been duly invited and if more than half the members who are entitled to vote are present. If, at the point in time stipulated, the General Assembly does not have a quorum, half an hour later the General Assembly with the same agenda takes place that, irrespective of the number of members present, has then a quorum and is regarded as properly constituted with the number of full members present.

**g)** A simple majority of the valid votes cast is required for a decision of the General Assembly of Voting Members. Resolutions regarding the amendment of the Statutes of the Association, extension of the president’s term with a third 2 years’ period or resolutions regarding the dissolution of the Association require a qualified majority of the valid votes delivered by two thirds of the Voting Members.

**h)** The Executive Committee chairs the General Assembly. The President of the Association shall act as chairperson of the General Assembly.

**i)** The minutes of the General Assembly shall be signed by the President and the Secretary. If one of these is unavailable to sign, a member of Executive Committee may sign on his/her behalf.

**j)** An extraordinary General Assembly has to be convened by the Executive Committee within four weeks:

1. upon decision of the Executive Committee;
2. upon decision of the Board;
3. upon written request of at least one-tenth of all Voting Members;
4. upon request of the Auditors;

The invitation must include an agenda of the items and all necessary supporting information or documents that should be discussed as well as the place and time of the meeting. Each extraordinary General Assembly shall be announced to the members in writing by the Executive Committee not later than four weeks before the event. A virtual (web-based) extraordinary General Assembly may alternatively be convened if deemed necessary by the Executive Committee and electronic voting by any means permitted by applicable law, including but not limited to electronic, internet, or email-based alternatives, is accepted as an adequate mean to take necessary decisions in a timely manner. It follows the same rules as outlined above. Voting procedures will be conducted in a manner providing for secrecy of the ballots and allowing one vote per person only.

**(2) The Board**

**a)** The Board is composed of Full Members with the following functions:

1. A National Representative or designated deputy from each Member Country. Where there are one or more Member Centres from a country which is not itself a SIOPEN Member Country, these organisation(s) shall select a National Representative who shall also become a member of the Board.
2. One Representative on behalf of all charities (CONE Group);
3. The Chairs of the Specialty Committees or designated deputies;
4. The Chairs of the Clinical Studies or designated deputies, during the time the study is open, during the follow-up period as specified in the study protocol and for the following year prior to publication;

The Advisory Board comprising previous Presidents acts in an advisory capacity at the Board level and should be invited by the Executive Committee without voting rights at Board and Executive Committee level;

An individual can be invited to attend a Board meeting by the Executive Committee for a specific purpose but does not have a voting right on the level of Board votes;

Commercial enterprises cannot vote, be part of the board or be elected into the steering structures.

**b)** The Board will meet at least twice a year.

**c)** The Board is empowered to define and approve the **strategy** and determine the **policy** of SIOPEN Group.

**d)** The Board has the responsibility to drive and coordinate the activities of the SIOPEN Group with respect to the **conduct of clinical studies** and **research** according to established specialty areas. New SIOPEN studies or major common scientific project proposals shall be presented to the Board for approval.

**e)** The Board is empowered to create or discontinue Specialty Committees, according to the needs of SIOPEN on the basis of individual single National Representative votes.

**f)** The Board is empowered to approve strategic positions within SIOPEN such as Study

Chair approvals.

**g)** The Board has the responsibility to establish and maintain the Association’s budget through fund raising activities and grant applications as individuals and/or through delegation to Full Members if adequate or third parties being legal entities. The Board defines and approves the annual financial contributions by Member Countries/Centres as suggested by the Treasurer.

**h)** The respective Board Members share the responsibility to ensure that the allocated amount for a respective Member Country/Centre or a specific SIOPEN project is raised and transferred within the set and agreed upon time period but not later than within the respective business period which extends to a maximum of one year. Thus annual membership contributions and fees to the SIOPEN Association per country as well as project specific support for the SIOPEN Association are regulated to allow the operation of the non-profit business affairs of the SIOPEN Association. Failure to comply in full may lead to Country/Centre membership termination.

**i)** The Board will suggest candidates for SIOPEN Presidency which will be voted through a ballot by all Full Members with voting rights at the General Assembly. For the reasons of continuity a future president of SIOPEN should have served at least one term at the Board level and in addition, ideally should have been once part of the Executive Committee for at least one term. Remote voting is acceptable if validity of the procedure can be assured as described in § 9 (1) a).

**j)** The location of the next Annual Meeting venue may be proposed by any Board Member and will be approved by the Executive Committee. The Full Board Member proposing the next AGM venue is responsible for the local organization of the AGM.

**k)** Voting rules within the Board: depending on the issue the Board will vote with the type of voting panel as decided prior to the meeting by the Executive Committee depending on the issue in question. Pending issues in need for a country vote need to be announced at least four weeks prior to the meeting to allow the countries to come to a decision and to give the mandate to their delegate.

**l)** All decisions of the Board will be made with a simple majority of the votes of the present Members. In the case of a tied vote, the vote of the President will decide.

**m)** Type of Votes within the Board:

*Single Country Vote:* In some circumstances a country vote is appropriate e.g. when clinical study issues are at stake. In this case, a National Representative will vote for each country. There will be one vote per country and the vote will be considered to represent the whole country. The voting member will be then identified in each country. Any issue requiring a country vote should be sent out in writing at least 4 weeks prior to the meeting where the ballot will take place to enable the country to come to a decision. A country vote could also take place by fax or other acceptable method as i.e. electronic voting.

*Representative Country Votes* are needed in issues where a more representative vote per country appears appropriate. In this case, the member voting for their country would have a number of votes proportional to the issue at hand e.g. proportional to the clinical study accrual numbers of the country or proportional to the population base of the country or proportional to the monetary status of the country in Europe.

*Ordinary Votes* within the Board shall be used for topics under discussion within the Board Meeting without previous announcements and in need of a decision. Each Board Member has a single vote irrespective of their country or affiliation to a legal entity.

**(3) The Executive Committee**

**a)** The Executive Committee is composed of:

1. A President with a term of office for two years, which may be extended for a second term and under exceptional circumstances for a third term up to a total maximum of six years, as described in § 8 (2),
2. The former President who will stay on the Executive Committee for a further year, without voting rights.
3. A President Elect for one year prior to taking up position of President; without voting rights unless he/she is member of the Executive Committee with voting rights.
4. Eleven Country Representatives being Full Members as follows:

Five Country Representatives from the current SIOPEN Member Countries with the highest accrual rates: France, Italy, Spain, United Kingdom, Germany: They have a term of office for four years, with 2 or 3 of these Country Representatives leaving every two years. Respective countries and the Board may nominate Country Representatives originating from the above countries. Nominated Country Representative Candidates will be elected with votes (ballot at spring or AGM meetings or electronic votes) respecting time periods of announcement of nominations at least 2 weeks prior to the voting process among all Full Members thus ensuring that each of the above countries will have a Country Representative elected by the General Assembly.

1. Six Country Representatives from the remaining SIOPEN Member Countries/Centres with a term of office for four years, with three of these Country Representatives leaving every two years. These Country Representatives are nominated and elected with votes according to voting processes as outlined above among all Full Members.
2. The Executive Committee may appoint up to three FM to serve on the Executive Committee on special mission. Such appointments to the Executive Committee should be validated by a General Assembly vote of approval. Such appointed executive Committee members can serve on the Executive Committee for up to four years, with yearly renewal. Only elected members of the Executive Committee have voting rights.
	* Two Executive Committee members will be designated as Deputy Presidents. This does not imply automatically the future position of President elect. In the event that there is a President elect as part of the Executive Committee, he or she will serve as Deputy President and may replace through his/her election one of the Deputy Presidents in office.
	* One Executive Committee member will be designated as Secretary;
	* One Executive committee member will be designated as Treasurer. In case his/her nomination should occur at his/her mid-term, a prolongation of 2 years as Past Executive Committee Member can be granted in order to fulfill a 4 year term.
* The total number of Full Members serving on the Executive Committee is up to fifteen but may be up to sixteen through the inclusion of the former President or President Elect, or even up to seventeen if a past Executive Committee member takes up the role of Treasurer.
* If a member of the Executive Committee wishes to retire from his/her function, the Executive Committee will call elections as specified for the respective positions.
* In summary: the Executive Committee can have up to 15 members and may have 16 if President Elect or Past President are included or 17 if a past Executive Committee member becomes treasurer:
	+ - 1 president
		- 5 Country Representatives from the current SIOPEN Member Countries with the highest accrual rates
		- 6 Country Representatives from the remaining SIOPEN Member Countries/Centres
		- 1-3 FMs to serve on special mission
		- 1 President Elect +/- Past President
		- 1 extra position if the Treasurer is a past Executive Committee member
1. Responsibilities of the Executive Committee

The Executive Committee is responsible for the management and the representation of the Association. It has to manage the Association with the diligence of a decent and conscientious institution according to these Statutes and the decisions of the General Assembly and the Board. It is responsible for all tasks that are not allocated to another body of the Association by virtue of the Statutes. In particular:

1. The **Executive Committee** is the final decision taking **Management Structure** of the SIOPEN Association after having consulted with the Board and General Assembly according to topic and may act on behalf the Board and the General Assembly under special circumstances and has the ultimate responsibility for the SIOPEN Association’s welfare.
2. The Executive Committee is required to execute decisions taken during the AGM by the General Assembly or at Board meetings by the Board.
3. The Executive Committee will be convened, physically or remotely, at least four times a year by the President, if he or she is unavailable, by the Deputy President. The President is the chairperson or, if he or she is unavailable, the Deputy President.
4. The quorum for meetings of the Executive Committee will be attendance of at least half the members. Management decisions will be taken by a simple majority vote. Where votes are equal the President may take the final decision.

**c)** Specific responsibilities within the Executive Committee:

1. In performing his/her activities the Full Members elected to the Executive Committee are obliged to use due diligence.
2. The President, if he or she is unavailable, the Deputy President or the Secretary or the Treasurer, is responsible for the representation of the SIOPEN Association to authorities and third parties.
3. Documents, in particular those that obligate the SIOPEN Association, have to be signed by the President and the Deputy President or if not available by another Executive Committee Full Member, and in financial matters jointly with the Treasurer.
4. The Secretary supports the President in performing the Association’s business. He/she is responsible for the preparation of the minutes of the General Assembly, the Board and the Executive Committee but may delegate this duty to other Full Members, if needed.
5. The Treasurer is responsible for the administration of the finances of the Association.
6. The Executive Committee is entitled and obliged:
7. to administrate membership applications according to the set rules
8. to provide for the regular performance of the activities
9. to provide a suggestion for the selection and appointment of the accountants and annual auditors, respectively
10. to select and discharge the financial administrator and auditor
11. to organise events
12. to manage the Association’s assets and to establish an accounting system
13. to prepare the profit and loss account including the statement of assets and liabilities according to § 21 Austrian Law of Association, and the annual accounts according to § 22 Austrian Law of Association in case of exceeding the threshold values according to § 22 Austrian Law of Association, respectively within 5 months after the end of the financial year.
14. to convene a General Assembly and Board meetings to report in these meetings about the activities and the finances
15. to establish or cancel employment contracts
16. to sign every agreement and contract and to coordinate every project assigned by the European Commission or by any regional, national or international entity, public or private, including donations
17. to propose changes in the Statutes and to seek approval by the Board and/or the General Assembly
18. to organise the Annual General Meeting (AGM) and the biannual Board Meetings. The Executive Committee will coordinate the AGM overall programme including the Board meeting, the calls for Study Committee meetings, the calls for Specialty Committee meetings and the main scientific programme.

The Executive Committee receives and approves Membership applications from prospective Member Countries/Centres.

**§ 10 Treasurer and accountants**

1. The treasurer is responsible for the management of the day-to-day business (day-to-day performance) and financial affairs of the Association.
2. The Executive Committee and the treasurer will timely provide all necessary documents so that the accountant and auditor are able to check the correctness of the accounting and the closing of accounts and annual accounts, respectively.
3. The day-to-day performance as well as the closing of accounts/annual accounts are subject to the revision of an independent and impartial auditor even if the qualification of § 22 Austrian Law of Association is not available. The auditor takes on the task of the accountants and can also be a legal entity (auditing company). The accountants must not belong to any institution, with the exception of the General Assembly, the activities of which are subject to the audit. The provisions for the accountants apply analogously also for the annual auditor.
4. The accountants are responsible for supervising the current transactions and for checking the financial performance of the Association in view of the correct financial accounting and the appropriate, economic use of the funds according to Statutes and the verification of the closing of accounts and annual accounts, respectively. Within four months after the preparation of the profit and loss account and the statement of assets and liabilities (according to § 21 Austrian Law of Association) and the annual accounts (according to § 22 Austrian Law of Association), respectively they have to perform an audit. The results of the audit will be written in a report that is provided to the Executive Committee and the General Assembly. The auditor has to immediately inform the president about particular details that he/she identifies during the continuous verification of the financial performance or the revision of the profit and loss account or the annual accounts.

**§11 Parents’ Associations and Charities**

**(1)** Premises

There already exist a limited number of nationally- based non-profit parental associations and charities which occasionally sponsor neuroblastoma research. With increased interaction and collaboration, these associations and charities could achieve greater importance for SIOPEN, and potentially influence the political factor and collect more funds.

**(2)** Objectives

**a)** To assist collaboration of existing nationally-based non-profit parental associations and charities with a special interest in neuroblastoma.

**b)** To stimulate the foundation of Neuroblastoma Support Groups (NSGs) in other countries participating in SIOPEN.

**c)** To identify individuals, responsible associations and charities of each NSG authorised to interact with SIOPEN.

**d)** To allow these representatives to attend meetings of SIOPEN as Associate Members.

**(3)** Representation in the Board

One representative of the parents’ Associations and Charities should be represented in the Board, without voting rights.

**§12 Profile and Function of SIOPEN Meetings**

**(1) Annual SIOPEN Meeting**

**a)** The President of the Executive Committee acts as the Chair of the Annual SIOPEN Meeting in case of absence, the Executive Committee will indicate a substitute.

**b)** The Annual General Meeting will include the following major sections:

1. A General Assembly of all Voting Members
2. Meeting of the Board
3. Option for Study Committee meetings
4. Option for Specialty Committee meetings
5. A scientific programme

The invitation to the General Assembly must be delivered to all members at least one month in advance.

**(2) Board Meetings**

The Board will meet twice a year, both at the Annual General Meeting and Spring Meeting of SIOPEN. Board members will be expected to attend at least one of these meetings.

**§ 13 Internal Court of Arbitration**

**(1)** The court of arbitration settles all disputes resulting from the Association’s relationship.

**(2)** All disputes arising out of these Statutes or related to its violation, termination or nullity shall be finally settled under the Rules of an Association - internal arbitration tribunal, which is not an Arbitral Tribunal in the terms of Art 577 et seqq. Austrian Civil Process Regulation.

**(3)** The location of the arbitration shall be in Vienna.

**(4)** The language to be used in the arbitral proceedings shall be English.

**(5)** It consists of three Association members of full age eligible into the Executive Committee and is composed in such a way that upon agreement about the involvement of the court of arbitration each party communicates one member as arbitrator to the Executive Committee within two weeks. Within further two weeks they elect a further member as chairperson; if there is a tie vote, the lot decides among the persons suggested. The Members of the Arbitration Court cannot belong to any party whose function is an issue of the dispute.

**(6)** The court of arbitration takes a decision with the majority of the votes in the presence of all members after granting reciprocal hearing. It has to take its decision to the best of its knowledge. An abstention from voting is not feasible.

**(7)** If the procedure at the court of arbitration is not terminated before, legal action with regard to disputes can only be taken after the expiry of six months after the agreement to involve a court of arbitration (§ 8 Austrian Law of Association 2002).

**(8)** The decision of the court of arbitration is irrevocable for the Association.

**§ 14 Dissolving the Association**

**(1)** The voluntary dissolution of the Association can only be decided in an extraordinary General Meeting of board members convened ad hoc and only with a majority of two thirds of the casted valid votes.

 **(2)** If assets of the Association exist – the General Meeting of board members has also to decide about the processing. In particular, it has to appoint a representative for the processing (liquidator).

**(3)** In case of voluntary dissolving, change of the purpose of the association or loss of the privileged purpose of the Association, the residual of the Association’s assets has to be used exclusively and directly for donation-privileged purposes pursuant to § 4a paragraph 2 line 1 and paragraph 3 line 4 to 6 Austrian Income Tax Act 1988. This provision is also valid in case of dissolution by official order.

 **(4)** Where possible, the residual of the Association’s assets should to be transferred to the following association: SIOP Europe, avenue E. Mounier, 83, 1200 Brussels, Belgium which pursues the same or similar purposes as this Association.

1. The dissolution of the Association is to be notified within four weeks in writing to the competent Austrian Authority (“Vereinsbehörde”) and is to be published in the “Amtsblatt der Wiener Zeitung”.

**APPENDIX I**

The SIOPEN Annual General Meeting is held in autumn each year. Thus, for reasons of ratification, the respective replacements within the SIOPEN Executive Committee should be made on the occasion of the SIOPEN Annual General Meeting. With this in mind, the SIOPEN Executive Committee decided at the SIOPEN Annual General Meeting held in London (UK) from 12-14 October 2011 to adjust the interval of the terms of office with a one-time interim arrangement. This adjustment is notified under § 8 (2a) accordingly. After this one-time transition period the terms of office are valid as stipulated under § 8 (2) in the Statutes of the Association.

**APPENDIX II**

On the occasion of the SIOPEN Annual General Meeting held on 26.11.2015 in Newcastle (UK), it was decided to adjust the terms of office to the calendar year. The annual accounts will be presented within a year. The budget for the current calendar year will be presented at the SIOPEN Annual General Meeting in autumn.

This is an adjustment of the terms of office according to above-mentioned decision taken by the SIOPEN Executive Committee.