



## *International Pompe Association*

---

Last changed: November 2009

### **STANDING RULES (BY LAWS) IPA**

#### *Membership*

##### **Article 1**

1. The IPA has full members and associated members.
2. Application for membership is done in writing (e-mail)
3. The board decides on admission as a member and the kind of membership (member-associated member). Each country has only one representative with voting right but it is to the discretion of the IPA board to admit other members from the same country. However only one representative has voting rights. Also it is up to IPA's representative in this country to work with a "splinter group".
4. Associated members, as defined in article 4.1 of the Statutory have equal rights and duties as full members with the exception of voting right, as is the determined in article 11.2 of the Statutory

#### *The board*

##### **Article 2**

1. Its members entrust the board with the responsibility for the leadership of the association.
2. The board meetings are held every two months as a rule and further on as often as the Secretary the Chairman or three board members deem necessary and give notice of this in writing to the other board members. In the last case the Secretary convenes a meeting in writing two weeks before this meeting is to take place.

#### *The Chairman*

##### **Article 3**

1. The Chairman presides all meetings. He signs the approved minutes of these meetings with the Secretary.
2. In the absence of the chairman he will be replaced by the vice chairman and if he is not present either, by one of the other board members, to be appointed by the board.

#### *The Secretary*

##### **Article 4**

1. The secretary takes care of the daily correspondence, the filing of the correspondence and transferring to his successor, the timely drawing up of reports, convocation of board meetings, taking down of minutes of board meeting and further more all tasks deemed to be included in his task.
2. In his absence the secretary is replaced by one of the other board members, to be appointed by the board.



## *International Pompe Association*

---

### *Finances*

#### **Article 5**

1. In the case of liquidation, remaining funds should be dedicated, after qualification, to a charity in accordance with IPA's mission
2. Double authorization (two board members) is required in case of money withdraw and payment of amounts exceeding 5.000 Euro.
3. The board is empowered to obtain external expertise in case of questions concerning civil law (e.g. liabilities in the context with website publications). The board will always decide this in its meetings it is not an empowerment for one single board member.
4. The Board and Advisory Board members shall be reimbursed for travelling-/ accommodation-/ telephone costs after pre-approval from the Chairman and the Treasurer
5. Reimbursement of km-expenses (when a private car is used) at 0,19 Euro per driven kilometre.

### *Contribution*

#### **Article 6**

1. The contribution is determined by the members during the AGM (Annual General Meeting).
2. The costs of attending the general meeting are for the account of the member.

### *Voting rights*

#### **Article 7**

1. When nobody requires a vote on the AGM, a decision is deemed to be accepted, with all general votes, unless someone requires a notation that he wants to be declared apposed to the proposal.
2. When somebody demands a vote, this will takes place with closed ballots, on oral matters by means of acclamation. If there is a deviation of the rule the voting procedure will be judged by the meeting.
3. Decisions are made by majority of votes, unless a special majority is required by general rules.
4. In case of equally division of the votes, a new vote will immediately be called. If the votes are divided once again the proposition is deemed to be rejected.
5. The chairman appoints a "polling-station" of three members, not being board members. The polling station will decide the outcome of the vote. Blank notes are marked invalid as well as those notes are not readable or on which superfluous remarks are made.

### *Change of regulations*

#### **Article 8**

1. Change of regulations can only take place by decision of the AGM.



## *International Pompe Association*

---

### *Special amendment*

#### **Article 9**

1. In all cases in which the standing rules do not anticipate the board decides.

### *Funding*

#### **Article 10**

1. Fundraising is not an objective of the IPA. IPA could be an intermediate for funding and is allowed to fundraise if needed for the activities, which are in the best interest of the IPA and its members.
2. The board is empowered to contract sponsors after having received specific expert opinion about the civil and tax consequences.

### *Guidelines advisors to the IPA board*

#### **Article 11**

1. Advisory board members may be requested to attend the IPA AGM and participate in IPA board meetings, only by specific request of the IPA board.
2. Advisory board members may represent IPA only when agreed or requested by the IPA board
3. Travel costs for IPA advisory board members will be reimbursed by the IPA if undertaken on behalf of the IPA and no other funding is available.