

19 February 2002

## **STATUTES**

*Name and registered office*

### **Article 1**

1. The society shall bear the name of: INTERNATIONAL POMPE ASSOCIATION
2. It shall have its registered office in the municipality of Baarn

*Object*

### **Article 2**

1. The object of the society shall be the combating of the illness of Pompe and the supporting of those who suffer from this illness.
2. It shall attempt to achieve this object, among other things, by:
  - a. the supplying of information;
  - b. the promoting of an earliest possible diagnosis;
  - c. the promoting of an affordable, effective and safe treatment of the illness.

*Duration*

### **Article 3**

The society is formed for an unlimited duration of time.

### **Article 4**

1. The society shall have members. There shall be two types of members:
  - a. full members;
  - b. associated members.
2. Full members shall be those patient organizations who actively occupy themselves with the object of the society.  
Associated members shall be groups, organizations and individuals who accept the mission and the objectives as defined in article 2.
3. Those who want to become members shall have to apply, in writing, to the board for membership, thereby indicating the type of membership. The board shall decide on whether or not to admit such applicant as member, as well as on the type of membership. This shall become apparent from a declaration issued by the board. In case of non-admission by the board the general members' meeting shall still be able to decide on admission. The general meeting can also decide on a kind of membership different from that on which the board decided.
4. The membership shall be personal and cannot be transferred or be acquired by succession.

### **Article 5**

1. The membership shall terminate:
  - a. dissolution of a member/patient organization;
  - b. ceasing to exist of a member/patient organization, because of, for example fusion;
  - c. by the decease of the member;
  - d. by the serving of notice by the member;
  - e. by the serving of notice by the society;
  - f. by removal.
2. The serving of notice of the membership by the member can only take place towards the end of a financial year. It shall be served, in writing, to the board, with due observation of a term of notice of at least four weeks. If notice should not have been served in time, the membership shall continue up to the end of the next following financial year.  
The membership shall terminate immediately:
  - a. if it cannot be demanded reasonably of the member that the membership continue;

- b. within a month of a decision, in which the rights of the members were limited or their obligations were increased, becoming known to a member or being communicated to the latter, unless this should concern a change in the financial rights and obligations;
- c. within a month of the communicating to a member of a decision on conversion of the society into a different legal form or on merger.
3. The serving of notice of the membership on behalf of the society can be done by the board towards the end of the current financial year:
- when a member, after having been summoned repeatedly, in writing, to this end, shall not have met in full his financial obligations vis-à-vis the society for the current financial year, on the first of November;
  - when the member shall have ceased to comply with the demands which at that moment should have been imposed on the membership by the articles of association.
- The term of notice shall be at least four weeks. If the notice should not have been served in time, the membership shall continue up to the end of the next following financial year. The serving of notice can, however, have the consequence of immediate termination of the membership, when it cannot reasonably be demanded of the society that the membership continue. Notice shall always be served in writing, with an indication of the reasons.
4. Removal from the membership can only be pronounced when a member acts in contravention of the articles of association, rules or decisions of the society or when the member harms the society in an unreasonable way. It shall be done by the board, which shall inform the member of the decision at the earliest opportunity, with an indication of the reasons for this. The member concerned shall be entitled to appeal to the general members' meeting within one month of receipt of the relevant notification. During the term of appeal, and pending the appeal, the member shall be suspended. A suspended member shall have no voting right.
5. If the membership should terminate in the course of the financial year, the member shall continue to owe the annual contribution for the entire year, unless the board should decide otherwise.

### *Contributions*

#### **Article 6**

Annually, every member shall have to pay a contribution. The amount of the contribution shall be fixed by the general members' meeting.

### *Board*

#### **Article 7**

1. The board shall consist of a minimum of three and a maximum of seven natural] persons, who shall designate from: their midst a chairman, a secretary and a treasurer. The positions of secretary and treasurer can be held by one person only
2. The board members shall be appointed by the general members' meeting. The board members can be appointed outside the members of the association. The general members' meeting shall fix the number of board members.
3. Board members can at all times be suspended and dismissed, with an indication of the reasons for this, by the general members' meeting. The general members' meeting shall decide on suspension or dismissal with a majority of two-thirds of the votes cast.
4. The suspension shall terminate when the general] members' meeting shall not have decided on dismissal within three months of this. The suspended board member shall be afforded the opportunity to justify himself at the general members' meeting and can have himself assisted in this by a counsel
5. Board members shall be appointed for a maximum period of three years. By a 'year' shall be meant here the period between two successive annual general members' meetings. The board members shall step down in accordance with a schedule to be drawn up by the board. A board member who steps down according to the schedule can be reappointed an indefinite number of times and immediately.
6. If the number of board members should have dropped below the minimum fixed in par. 1, then the board shall nevertheless remain competent. The board shall be obliged to convene a general members' meeting at the earliest opportunity, in which the filling of the vacancy (vacancies) shall be put on the agenda.
7. To the meetings and the decision-making by the board the clauses in the articles 10 up to and including 13 shall be applicable as much as possible.

## **Article 8**

1. The board shall be charged with the managing of the society.
2. With the prior approval of the general members' meeting the board shall be authorized to decide to enter into agreements for the acquisition, alienation or encumbrance of register-bound goods and to enter into agreements in which the association shall oblige itself as guarantor or jointly and severally liable co debtor, make every effort on behalf of a third party, or oblige itself as guarantor for the debt of another.

## **Article 9**

1. The board shall represent the society.
2. to the power of representation shall also be entitled the chairman, together with the secretary or the treasurer, or the secretary together with the treasurer.

### *General members' meetings*

## **Article 10**

The general members' meetings shall be held in the place to be stated in the written convocation for the general members' meeting

## **Article 11**

1. Admission to the general members' meeting shall have those members that have not been suspended, together with those who shall have been invited by the board and/or the general members' meeting. A suspended member shall have admission to the meeting at which the decision on his suspension shall be dealt with, and shall be entitled to hold forth on this.
2. With the exception of a suspended member every full member shall have one vote at the general members' meeting. Every member entitled to vote can authorize another member entitled to vote, in writing, to cast his vote. A member entitled to vote can act as proxy on behalf of a maximum of two persons. Associated members shall exclusively have the right to attend the general members' meeting. They shall have no right to vote there, but they shall have the right to speak there.
3. A unanimous decision by all members entitled to vote, even if they should not be present at a meeting, shall have the same force, provided it was taken with the prior knowledge of the board, as a decision of the general members' meeting. This decision can also come about in writing.
4. The chairman shall decide on the way in which voting shall take place at the general members' meeting.
5. All decisions on which, by law or according to these articles of association, no larger majority should have been prescribed, shall be taken by absolute majority of the votes cast. In case of a tie about matters the proposal shall have been rejected. Should the votes equally divide in the election of persons, then lots shall be drawn. If in an election between more than two persons, no one should have obtained an absolute majority, then there shall be another vote between the two persons who obtained the largest number of votes, if necessary after an intermediary vote.

## **Article 12**

1. The general members' meetings shall be led by the chairman or, in the latter's absence, by the board member to be appointed by the meeting. -If no board members should be present, then the meeting itself shall provide for its guidance.
2. The judgment, pronounced by the chairman at the general members' meeting, on the result of a vote shall be decisive. The same shall apply to the contents of a decision made, in so far as voting took place on a proposal not laid down in writing. However, if, immediately after the pronouncing of the judgment by the chairman, the correctness of this should be disputed, then a new vote shall be held, if the majority of the meeting or, if the original vote should not have taken place per head or in writing, a person present and entitled to vote should demand this. Through this new vote the legal consequences of the original vote shall lapse.
3. Of the items dealt with at the general members' meeting, minutes shall be kept by the secretary or by a person designated by the chairman. These minutes shall be adopted at the same, or at the next following, general members' meeting and as proof of this they shall be signed by the chairman and the secretary of that meeting.

## **Article 13**

1. The financial year of the society shall run parallel to the calendar year. Annually, at least one general members' meeting shall be held, namely within six months of the expiry of the financial year, subject to extension of this term by the general members' meeting. At this general members' meeting the board shall submit its annual report on the course of things within the association and on the policy conducted. It submits to the general members' meeting the balance and the statement of revenue and expenditure, with an explanatory note, for its approval.

These documents shall be signed by the board members; should the signature of one or more of these be lacking, then mention of this shall be made, with the reasons for this. After expiry of the term every member can legally demand of the joint board members that they fulfill these obligations.

2. If no declaration, about the reliability of the documents meant in the preceding paragraph and originating from an accountant as meant in article 2:393, par. 1, of the Civil Code, should be submitted to the general members' meeting, then the general members' meeting shall annually appoint a committee of at least two members who shall not be allowed to form part of the board.

3. The board shall be obliged to provide the committee, for the purpose of its examination, with all information requested by it, to show it the cash and the values, if desired, and to offer it perusal of the books and documents of the society .

4. The committee shall examine the documents meant in par. 1 and par. 3.

5. If this examination, at the discretion of the committee, should require special accounting knowledge, then it can have itself assisted, at the expense of the society, by an expert. The committee shall report its findings to the general members' meeting.

## **Article 14**

1. General members' meetings shall be convened by the board as often as it shall deem this desirable or shall be obliged to do so on the basis of the law.

2. Upon written request of at least one-tenth part of the members entitled to vote the board shall be obliged to convene a general members' meeting, to be held within four weeks of such request.

3. The convocation to the general members' meeting shall be made by written notice, served to those entitled to vote within a term of at least seven days. In the convocation the subjects to be dealt with shall be listed.

### *Change in the articles of association*

## **Article 15**

1. A change in the articles of association can only be made by a decision of the general members' meeting, which shall have been convened with the notice that a change in the articles of association shall be proposed there.

2. Those who shall have drawn up the convocation to the general members' meeting for discussion of a proposal for a change in the articles of association, must deposit - at least five days prior to the date of the meeting and until after the end of the day on which such meeting was held - a copy of that proposal, in which the proposed change has been quoted literally, at a locality suitable to this end, for perusal by the members.

3. The general members' meeting can only decide on a change in the articles of association, with a majority of at least two-thirds of the number of votes cast. 4. The change in the articles of association shall only take effect after a notarial deed shall have been drawn up.

Each of the board members shall be entitled to arrange for passing of the deed of a change in the articles of association.

5. The clauses in the paragraphs 1 and 2 shall not apply if, at the general members' meeting, all those entitled to vote shall be present or represented and the decision to change the articles of association shall be made unanimously.

6. The board members shall be obliged to deposit an authentic copy of the deed of the change in the articles of association and a complete, continuing text of the articles of association - in the way as these shall read after the change - at the office of the register kept by the Chamber of Commerce and Factories.

## *Dissolution and liquidation*

### **Article 16**

1. The clauses in article 15, par. 1, 2, 3 and 5, shall apply correspondingly to a decision of the general members' meeting to dissolve the society.
2. In its decision, meant in the previous paragraph, the general members' meeting shall determine the appropriation of the credit balance, and this as much as possible in conformity with the object of the society.
3. The liquidation shall be carried out by the board.
4. After the dissolution the society shall continue to exist, in so far as this should be necessary for the liquidation of its capital. During the liquidation the clauses of the articles of association shall remain in force as much as possible. In documents and announcements, issued by the society, the words 'in liquidation' shall have to be added to its name.
5. The liquidation shall terminate on the date on which no longer any assets, known to the liquidator, shall be present.
6. The books and documents of the dissolved society shall have to be kept for seven years following the completion of the liquidation. Custodian shall be the person who shall have been designated as such by the liquidators:

## *Regulations*

### **Article 17**

- 1 The general members' meeting can adopt and change one or more regulations, in which subjects shall be regulated for which these articles of association should have made no, or no complete, provision.
2. Rules and regulations may not contain any clauses that should be inconsistent with the law or with these articles of association.
3. To decisions on adoption of and on change in regulations the clauses in article 15, par. 1, 2 and 5, shall apply correspondingly.

## *Final clause*

### **Article 18**

The general members' meeting shall have all powers in the society which the law or the articles of association shall not have entrusted to other bodies.

## **Final declarations**

Finally, the persons appearing declared

As first board members are appointed:

1. the appearing party sub 1 [Randall House], in the position of chairman;
2. the appearing party sub 2 [Ria Broekgaarden, in the position of secretary/treasurer;
3. Mister Kevin ... O'Donnell..., in the position of general member of the committee;
5. Misses ... Maryze Schoneveld..., in the position of general member of the committee.

The first office address of the society shall be: Luitenant-Generaal Van Heutszlaan 6 (3743 JN) Baarn. The current financial year of the society shall end on the thirty-first of December of two thousand and two. In the event of any textual interpretation problems because of the two languages of this deed, the Dutch text will prevail. The appearing parties are known to me, the notary. -So drafted and minuted at Baarn on the date as first before mentioned. After being informed of the essential statements and content of this deed, and the giving of an explanation thereof to the appearing parties by me, the notary, where necessary they were informed of the consequences, after which they declared unanimously that they had already familiarized themselves with the content of this deed and agreed therewith, as well as with the limited reading of this deed; after which this deed was signed, immediately following the limited reading thereof, by the appearing parties and then by me, the undersigned notary.