

PHEOCHROMOCYTOMA AND PARAGANGLIOMA RESEARCH SUPPORT ORGANIZATION (PRESSOR)

CONSTITUTION

ARTICLE I: NAME

The name of the organization is the **Pheochromocytoma and Paraganglioma Research Support Organization (PRESSOR)**

ARTICLE II: PURPOSE

The organization consists of a consortium of health science professionals at scientific, medical and academic institutions around the world dedicated to research into improved diagnosis, localization, management and treatment of pheochromocytoma and paragangliomas (PHEO/PGL), particularly malignant PHEO/PGL. The purpose of the organization is to promote research and facilitate collaboration and the sharing of materials, information and expertise among investigators, scientists and clinicians interested in pheochromocytomas, paragangliomas, and other related tumors. The organization will promote improved understanding and research into these tumors, co-ordinate clinical and scientific meetings to develop best practice in their care and management, promote and disseminate scholarship, interest and information, and act as a forum for patient information and the promotion of clinical trials and training.

The nature and organization of all activities shall be planned and organised by the PRESSOR Executive Committee.

The income and property of the Organization shall be applied solely towards the promotion of the purposes of the Organization as set out in this Article, and no portion thereof shall be paid or transferred directly or indirectly by way of dividend, bonus or by any other way of profit or pecuniary gain to members of the Organization. In the event that the Organization is dissolved, any surplus property will be distributed as decided by the Executive Committee at that time.

ARTICLE III: MEMBERSHIP

Membership is open to all who have an interest in PHEO/PGL from a clinical, scientific or patient-orientated perspective. Membership is conferred upon application to the Membership secretary with written support of at least one member of the Executive Committee. Payment of membership fees will vary according to the decision of the Executive Committee at that time. If it is decided that such membership fees are mandatory, then it will confer certain advantages and privileges not available to non-paying members. If a member is more than one year in arrears with his/her membership dues, those privileges and advantages are revoked.

ARTICLE IV: OFFICERS

Section 1:

The Executive Committee consists of Officers named below in Section 2.

Section 2:

The Officers of the Organization shall constitute an Executive Committee consisting of a President, a Chairperson (the latter may be shared as co-Chairs by two individuals), Immediate Past-chair(s), a Treasurer, a Membership officer, an Administrative officer, a Secretary, Funding officer(s), Information

officer(s), Publications officer(s), Liaison officer(s) and Conference officers. The latter five positions may each be filled by one or multiple individuals.

The areas of responsibility are listed below:

President – Senior member elected to the position in an advisory capacity for the chairperson(s)

Chairperson(s) – Overall responsibility for the Organization and calling of Executive Committee meetings

Treasurer – Responsibility for collation and disposal of funds

Membership Officer – Responsibility for membership

Administrative Officer – Responsibility for legal issues

Secretary – Organization of Executive Committee meetings and taking minutes

Funding Officer(s) – Responsibility for registry of applicable funding resources

Information Officer(s) – Responsibility for patient registry, SOPs

Publications Officer(s) – Responsibility for website and newsletter

Liaison Officer(s) – Responsibility for relations with outside organizations where appropriate including patient groups, pharmaceutical companies, working groups, international representatives and other consortia

Conference Officer(s) – This should be the nominated organiser of the next international conference, who will be an *ex officio* member of the Executive Committee.

The Chairperson(s) shall be elected for a term of three years, with no re-election to that position, and shall serve as Chair(s) of the Executive Committee. On completion of their terms of office, the Chairs will serve as Immediate past-Chairs for a term of 3 years, unless selected to another Officer position in the Organization, in which case the position of office of Immediate Past-Chair(s) will remain vacant for that term.

All other members of the Executive Committee shall also serve terms of 2 years, pursuant to selection by Chair(s), extendable on mutual agreement to 4 years. These members will be either selected from members of the previously established committee or from nominations submitted to the newly elected chairs. On initial formation the Executive Committee shall be selected by the Chair(s). After the formation of the Organization, the Committee members shall be elected by democratic election from the membership from 4 years.

The Executive Committee shall appoint a Patient Advisory Board with representatives from patient advocacy groups, answerable to the Liaison Officer(s) in the first instance. The Committee shall also appoint an International Advisory Board with representatives from all participating major nations or regions, answerable to the Liaison Officer(s) in the first instance, and responsible for linking to all members and patient support groups in participating nations, information on local funding and relevant news/information, membership recruitment and information dissemination. In addition, the Committee will appoint Leaders of Working Groups (4 year terms), who all shall be members of the Organization and will be answerable to the members of the Liaison Officer(s). The Working Groups will assist the Conference Officer(s) in organizing the break-out sessions of the International Symposia, will assist the Information Officer(s) in creating SOPs and will assist the Publications Officer(s) in providing articles for the website and newsletter.

The Executive Committee shall meet a minimum of once annually, plus extraordinary meetings if deemed necessary. Reasonable funds for transport and expenses shall be paid to Committee members, as funds allow. A minimum of 4 members of the Committee shall be deemed quorate. A full-committee meeting will be held after the close of every International Symposium of the Organization.

ARTICLE V: ELECTIONS

Section 1

Elections of co-chairs shall take place every 3 years in conjunction with the International Symposia of the Organization. Elections of Executive Committee members except for the Conference Officer(s) shall take place every 4 years. If any office becomes vacant between elections, the Executive Committee may select an interim replacement to the office to serve for the remaining term.

Section 2

The Secretary shall send notices to all members, requesting nominations for co-chairs as well as for Executive Committee members. If the number of nominations for any office exceeds the number of vacancies an email ballot shall be held.

ARTICLE VI: FINANCES

Section 1

The Executive Committee will engage in the financial transactions necessary for the operation of the Organization.

Section 2

Voluntary contributions may be solicited by the Society, at the discretion of the Executive Committee.

Section 3

The Treasurer shall report the financial status of the Society to the Executive Committee at least annually.

ARTICLE VII: INTERNATIONAL CONFERENCES

International symposia of the Organization will be held at a minimum of three-yearly intervals to collate and disseminate information of the latest scientific and clinical studies on the aetiology, diagnosis and management of PHEO/PGL, in order to disseminate best practice and facilitate training and knowledge. It will be an open meeting for members and non-members, and will include patient representatives. The venue of each subsequent meeting will be decided during the preceding meeting after a call for nominations by the Executive Committee from the membership. Those nominated will be entitled to present their plans at the symposium. A vote by those present may be called. Only members will be entitled to be nominated and vote for a location. The final decision will be reached through meeting of the Executive Committee after the close of each Symposium, taking into account geographical rotation.

ARTICLE VIII: AMENDMENTS

This Constitution may be amended, or bylaws may be added, following approved suggestions brought forward to the membership by the Executive Committee, by a majority decision of those members voting at annual dinner meetings or by an email ballot of the entire membership.