



## **1 Introduction**

- 1.1 PACTALS stands for “Pan-Asian Consortium for Treatment and Research in Amyotrophic Lateral Sclerosis.”

## **2 Mission and Vision**

- 2.1 PACTALS aims to achieve the following objectives:
- 2.1.1 Developing an Asia-Pacific network of researchers and clinicians working with ALS/MND that:
    - is recognized within the international ALS/MND network
    - can work collaboratively in an efficient and effective manner
    - will attract pharmaceutical companies to conduct trials in Asia-Pacific region
    - will support the education and training of members to achieve the overall objectives
  - 2.1.2 Establishing a Patient Registry within the Asia-Pacific region that will facilitate the collection/storage of clinical data.
  - 2.1.3 Initiating collaboration between funding agencies in Asia-Pacific to collectively sponsor investigator-initiated clinical trials.

## **3 Membership**

- 3.1 Clinicians, researchers and allied health professionals working within the ALS/MND community as well as representatives from ALS/MND associations and International Alliance of ALS/MND Associations who express an interest to be part of the group and its activities.
- 3.2 Membership benefits include networking opportunities and access to information about PACTALS conferences and workshops.
- 3.3 Membership is free and there are no specific obligations.

## **4 Leadership structure**

PACTALS is led by a dedicated group of individuals responsible for overseeing its operations and strategic direction. The leadership structure of PACTALS includes the following key positions:

- 4.1 Executive committee:
- 4.1.1 The Executive Committee is comprised of the President, President-Elect, Past-

Presidents, the next congress convenor, Secretary and Treasurer.

4.1.2 The Executive Committee's functions include:

- selecting venues for the scientific PACTALS meetings,
- supporting the scientific meeting,
- advising and appointing working groups,
- shaping academic content,
- making conference decisions,
- recognizing award winners.

4.1.3 Appointment and duties of the President and President-elect of PACTALS:

4.1.3.1 The President and President-elect are appointed at the **General Assembly** held during the PACTALS conference.

4.1.3.2 The President-elect will be the convenor of the current PACTALS conference and will assume the position after the completion of the conference. In the event the role is declined by the convenor, the Executive Committee shall appoint other suitable candidate either from the host country or other PACTALS member countries.

4.1.3.3 The duties of the President are as follows:

- i) To provide overall leadership for the organization
- ii) To preside over meetings, set agendas and ensure meetings are conducted effectively

4.1.3.4 The duties of the President-elect are as follows:

- i) To understand the duties of the President in preparation of future leadership
- ii) To fill in for the President during absences or disabilities
- iii) May be assigned specific tasks or responsibilities by the President or the Committee

4.1.4 Appointment and duties of the Secretary of PACTALS

4.1.4.1 The Secretary shall be appointed by the Executive Committee and approved by majority consensus of the country leads

4.1.4.2 The appointment will take into consideration their relevant skills, experience, and commitment to PACTALS mission

4.1.4.3 The Secretary shall serve a term of four (4) years.

4.1.4.4 The duties of the Secretary includes:

- i) Assisting the President in coordinating meetings and activities

- ii) To work where relevant, with the Secretariat, in preparing and circulating notices, agendas, and minutes of meetings.
- iii) Ensuring safekeeping of organizational archives and compliance with governance procedures.
- iv) May be assigned specific tasks or responsibilities by the President or the Committee

#### 4.1.5 Appointment and duties of the Treasurer of PACTALS

- 4.1.5.1 The Treasurer shall be appointed by the Executive Committee to oversee the financial management of PACTALS and approved by majority consensus of the country leads.
- 4.1.5.2 The appointment will take into consideration their relevant skills, experience, and commitment to PACTALS mission.
- 4.1.5.3 The duties of the Treasurer includes:
  - i) Financial management of the organization, including handling receipts, disbursement, and recording of all funds.
  - ii) Maintaining accurate and up-to-date accounts.
  - iii) Preparing annual financial reports for the ExCo and General Assembly.
  - iv) Advising on financial planning and sustainability of the organization.

#### 4.2 Country Leads and representatives

- 4.2.1 The Country representatives group consists of a maximum of three representatives per country, with a limit of one representative per ALS center within each country, when this is applicable.
- 4.2.2 One person shall be appointed the lead to represent the Country Representatives.
- 4.2.3 Functions of Country Lead and representatives:
  - Advising PACTALS.
  - Conveying key messages to and from their home country for committee discussions

#### 4.3 Scientific Committee:

- 4.3.1 The Scientific Committee is responsible for critical scientific and academic decisions within PACTALS, including conference program planning and award winner selection.
- 4.3.2 Functions of Scientific Committee:
  - Deciding the conference program
  - Deciding the PACTALS award winners

4.3.3 The Executive Committee will serve as the Scientific Committee until PACTALS establishes its membership fully.

4.4 *Ad hoc* Committees and Task Forces:

PACTALS may establish *ad hoc* committees or task forces as needed to address specific research, administrative, or operational matters. The creation, composition, and scope of these committees shall be determined by the Executive Committee.

5 **Meetings and Communication**

PACTALS holds meetings to facilitate communication, collaboration, which is dedicated to advancing research in ALS. These meetings may include but are not limited to:

5.1 The General Assembly will be held at the main PACTALS conference. Attendees will include the Executive Committee members, country leads, and country representatives.

5.2 Scientific Conference:

5.2.1 The scientific conference serves as a cornerstone of PACTALS's mission and objectives, providing a vital platform for researchers, clinicians, and stakeholders to convene, collaborate, and contribute to the advancement of ALS research.

5.2.2 The Congress Convenor hosts the scientific conference. This responsibility includes hosting the conference in their home country or in collaboration with a member institution, ensuring its successful planning, execution, and alignment with PACTALS' goals.

5.2.3 The conference shall aim to achieve the following key objectives:

- Facilitate the exchange of scientific findings and insights among professionals dedicated to ALS research.
- Encourage multidisciplinary collaboration among researchers, clinicians, and stakeholders.
- Provide a platform for the presentation of groundbreaking research and the sharing of best practices.
- Promote the mission and values of PACTALS within the ALS research community.

5.2.4 The Congress Convenor and the President shall work closely with the Executive Committee and other relevant parties to ensure the successful planning and execution of the conference, including logistics, program development, and participant coordination.

5.2.5 The Congress Convenor is empowered to modify the conference's structure, theme, or format, as necessary, to better address the missions and evolving goals of PACTALS.

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5.2.6 Collaborations and Cooperation: To ensure the success of the conference, collaboration and cooperation between the President, the Executive Committee, Country leads and representatives are essential. These parties shall work closely together to coordinate logistics, develop the program, and ensure the active participation of all relevant stakeholders.

5.3 Irregular meetings: Members are encouraged to propose irregular meetings or discussions to address specific issues, challenges, or opportunities related to ALS research. These meetings may be proposed to the Country Lead, who, in turn, may suggest them to the Executive committee for consideration.

5.4 Meeting notices: Notices shall be distributed via electronic means, such as email or an online platform.

## **6 Finance**

6.1 Financial responsibility: PACTALS acknowledges its multi-country organizational structure and the complexity of financial matters in a diverse international consortium. As such, PACTALS assigns the role of managing and overseeing the financial aspects of the organization within their own country to the Congress convenor, who is responsible for hosting the scientific conference.

6.2 Conference budgeting:

6.2.1 The Congress convenor, who is responsible for hosting the scientific conference, shall play a central role in managing and overseeing the financial aspects of this conference within their own country.

6.2.2 This budget shall encompass all aspects of conference organization, including venue rental, speaker invitations, attendee logistics, marketing, tax, and any associated costs.

6.2.3 In case any surplus funds generated from the conference, after covering all expenses, shall be reinvested in the consortium's future conferences. It can also be used in other research initiatives further advancing the mission of PACTALS after discussion with the executive committee.

6.3 Financial Oversight: The congress convenor is responsible for managing the funds. If necessary, the Congress Convenor may request financial support from the Executive Committee, and the Executive Committee will provide assistance to the best of their abilities.

6.4 Remuneration and expenses: The members of the Executive Committee will not be entitled to any personal remuneration or expenses from the PACTALS account.

## **7 Amendment and Review Process**

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PACTALS recognizes that its regulation and bylaws may need to be updated or modified from time to time to adapt to changing circumstances, ensure compliance with legal requirements, and better serve the consortium's objectives. Amendments to these regulation and bylaws may be proposed and considered as follows:

- 7.1 Proposal: Any member of PACTALS, including the Executive Committee or country lead and representatives, may propose an amendment to the regulation and bylaws. The proposed amendment shall be submitted in writing.
- 7.2 Review: The proposed amendment shall undergo a review process led by the Executive Committee, which will assess its compatibility with the consortium's mission and objectives, legal compliance, and potential implications.
- 7.3 Member Input: Input from all PACTALS members shall be sought and considered during the review process. Members will have an opportunity to provide feedback and suggestions related to the proposed amendment.
- 7.4 Approval: Amendments to the regulation and bylaws shall require approval by a 50% majority vote of the member country leads. A vote for approval can be requested in person or in writing and can proceed once a quorum of 30% is reached.
- 7.5 Notification: Upon approval of any amendments to the regulation and bylaws or the completion of a periodic review, PACTALS shall promptly notify all members of the changes and provide them with updated copies of the documents.
- 7.6 Record keeping: PACTALS shall maintain records of all amendments made to the regulation and bylaws, as well as documentation related to periodic reviews, for reference and historical purposes.

## **8 Secretariat**

A secretariat may be employed directly or by contract by the Executive Committee to manage activities at PACTALS, including the central organization of PACTALS conferences, in collaboration with the local organizers.

## **9 Effective date**

These regulation and bylaws of the Pan-Asian Consortium of Research in Amyotrophic Lateral Sclerosis (PACTALS) were formally discussed and ratified. All provisions herein shall be in effect from the effective date of this document.