

## Terms of Reference

### IPWSO Professional Providers and Caregivers Board (PPCB)

**Last approved:** This TOR was approved by the PPCB on 18 October 2022 and the IPWSO Board of Trustees on 21 November 2022.

**Review date:** This TOR will be next reviewed by the PPCB in consultation with the IPWSO Board of Trustees in early 2025 prior to the IPWSO 2025 Conference.

**Purpose:** The purpose of the PPCB is to bring best practice, information, knowledge and techniques to those providing care to the global PWS community, in order that those living with PWS may live their lives to the highest quality.

**Activities:** The activities of the PPCB include, but are not limited to:

- a) Reviewing and revising any materials containing information about professional caregiving that is made available by IPWSO to the public;
- b) Preparing and disseminating information about professional caregiving for the benefit of professional caregivers and the global PWS community;
- c) Representing the PPCB at in-person or online meetings to discuss matters relating to professional caregiving;
- d) Designing and hosting a Caregivers' Program as part of IPWSO's triennial international conference;
- e) Designing and hosting stand-alone Caregivers' Conferences;
- f) Attending in person site-visits of international PWS programs;
- g) Providing training and mentorship to professional caregivers of people with PWS;
- h) Ensuring PPCB tools and materials are accessible for the global caregivers' community;
- i) Advising IPWSO Trustees or others within IPWSO relating to provider or caregiver issues.

### **Membership:**

- The membership of the PPCB will comprise professional caregivers and providers of people with PWS.

- The PPCB will have a minimum of 6 members and may include as many additional members as are necessary to perform its work.
- The PPCB will include in its membership at least one IPWSO Trustee who will be nominated by the IPWSO President.
- The IPWSO President or CEO may appoint one IPWSO staff member to the PPCB.
- The PPCB will meet online or in person at least 4 times a year.
- PPCB members will be eligible to serve a maximum of 3 consecutive 3 year terms, with the exception of PPCB members who have served as the PPCB Chair. Chairs and former Chairs will be eligible to serve a maximum of 4 consecutive 3-year terms.
- A PPCB member who has served 3 consecutive terms may serve one or more additional terms after a gap of at least 1 year.
- The PPCB will review its membership in advance of each triennial IPWSO Conference and ascertain whether the existing members are available and willing to actively participate for a second or third term, and whether new members are needed.
- Participation in the PPCB is by invitation-only and the membership proposed by the PPCB will be submitted to the IPWSO Board for consideration and approval in advance of each triennial IPWSO Conference.
- A Chair will be selected by the PPCB at the IPWSO triennial conference and may serve for a maximum of 2 consecutive 3 year terms. A Vice Chair may also be selected at this time to assume the Chair position after the next triennial meeting.

***Responsibilities and Conflicts of Interest:***

1. All PPCB members are expected to uphold the values and pursue the mission of IPWSO.
2. The PPCB will report to the IPWSO Board of Trustees annually on its previous year's activities for inclusion in IPWSO's Annual Report.
3. If requested, the PPCB will prepare a summary of proposed activities to be included in the IPWSO Strategic Plan for consideration by the IPWSO Board of Trustees.
4. The Chair of the PPCB or their nominee should where possible attend the IPWSO Board of Trustee meetings and report on their activities of the PPCB. In the event of being unable to attend, the Chair or their nominee should update the Board by another means.
5. If the PPCB wishes to engage in an activity that is outside the scope of this TOR, the Chair of the PPCB will first seek approval from the IPWSO Board of Trustees for the revision of the TOR.
6. Written materials and other resources produced by the PPCB will be the property of IPWSO.

7. The PPCB may submit funding requests to the IPWSO Board of Trustees. If funding is approved, it will be the responsibility of the PPCB to ensure that relevant IPWSO policies and procedures, including those relating to financial management and purchasing, are adhered to.
8. The PPCB will ensure that any projects it oversees for which donor funding has been received are compliant with the terms and conditions of the donor.
9. Members of the PPCB shall act with due care and diligence in accordance with Charity Commission Rules, Data protection regulations, and the Code of Conduct, Policies and Procedures and Values of IPWSO.
10. All PPCB members are volunteers and any actions performed by the PPCB should be in the best interest of IPWSO and cannot personally profit any PPCB members. Each individual shall disclose to the PPCB any actual or perceived conflict of interest, or any circumstance that might be viewed by others as a conflict of interest, as soon as it arises. PPCB members may not vote on matters affecting their own interests and will submit to the judgement of the PPCB as to whether they should refrain from participation in discussions in which they have an interest. The minutes of PPCB meetings will record whether any interests were declared.