

## Terms of Reference

### IPWSO Clinical and Scientific Advisory Board (CSAB)

*This Terms of Reference (TOR) was approved by the CSAB on November 14, 2022 and the IPWSO Board of Trustees on 21 November 2022.*

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

#### **Purpose**

The purpose of IPWSO's CSAB is to provide expert clinical and scientific guidance to IPWSO and to undertake the activities listed below.

#### **Activities**

1. Providing global clinical and scientific leadership on PWS by promoting discussion and clinical and scientific debate, including preparing and submitting expert papers for publication in the clinical and scientific literature.
2. Encouraging research and promoting the best clinical, scientific and research practice for the benefit of clinical professionals and the global PWS community.
3. Reviewing and advising on materials containing information about clinical and scientific matters produced by IPWSO to ensure they meet the highest standards of scientific rigour and accuracy.
4. Responding to requests for advice from the IPWSO Board of Trustees and staff, which may include providing direct responses to queries from individual families, professionals and PWS associations.
5. Attending in-person or online meetings to discuss relevant clinical and scientific matters.

6. Designing and hosting a Clinical and Scientific Program as part of IPWSO's triennial International Conference.
7. Participating in ad hoc meetings and events organised by IPWSO.

### **Membership**

- The membership of the CSAB will comprise clinicians and scientists who have together a broad range of relevant clinical and/or research experience and through their clinical leadership and/or publications are recognised experts in the field of PWS.
- The CSAB will have a minimum of 8 members and may include as many additional members as are necessary to perform its work.
- The CSAB will include in its membership at least one IPWSO Trustee who will be nominated by the IPWSO President.
- The IPWSO President or CEO will appoint one IPWSO staff member to the CSAB.
- The CSAB will meet online or in person at least 4 times a year.
- CSAB members will be eligible to serve a maximum of 3 consecutive 3 year terms, with the exception of CSAB members who have served as the CSAB Chair. Chairs and former Chairs will be eligible to serve a maximum of 4 consecutive 3-year terms. Terms for Board member will officially begin after the triennial meeting.
- A CSAB member who has served 3 consecutive terms may be invited to rejoin the CSAB after a gap of at least 1 year. This will create a 10 year cycle that may be repeated.
- The CSAB will review its membership in advance of the 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 CSAB is by invitation-only and the membership proposed by the CSAB will be submitted to the IPWSO Board for consideration and approval in advance of the triennial International Conference.
- New CSAB members may also be invited by the CSAB to join midway through a term and in this case will be eligible to stand for a maximum of 3 additional terms.
- A Chair will be selected by the CSAB at the IPWSO triennial meeting 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.
- Board members' terms will end after the triennial meeting with the exception of the Chair whose term will officially end one month after the triennial meeting. This will allow the Chair time to prepare the CSAB report from the triennial meeting for the Board of Trustees.

### ***Responsibilities and Conflicts of Interest***

1. All CSAB members are expected to uphold the values and pursue the mission of IPWSO. The Board of Trustees will provide oversight to the CSAB to ensure members are acting ethically and responsibly.
2. The CSAB 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 CSAB 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 CSAB or their nominee should where possible attend the IPWSO Board of Trustee meetings and report on the activities of the CSAB. In the event of being unable to attend, the Chair or their nominee should update the Board by another means.
5. If the CSAB wishes to engage in an activity that is outside the scope of this TOR, the Chair of the CSAB 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 CSAB will be the property of IPWSO.
7. The CSAB may submit funding requests to the IPWSO Board of Trustees. If funding is approved, it will be the responsibility of the CSAB to ensure that relevant IPWSO policies and procedures, including those relating to finance and purchasing, are adhered to.
8. The CSAB will ensure that any projects it oversees for which donor funding has been received is compliant with the terms and conditions of the donor.
9. Members of the CSAB shall act with due care and diligence in accordance with Charity Commission Rules, data protection regulations, and IPWSO's Code of Conduct and policies and procedures.
10. All CSAB members are volunteers and any actions performed by the CSAB should be in the best interest of IPWSO and cannot personally profit any CSAB member. Each member shall disclose to the CSAB 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. CSAB members may not vote on matters affecting their own interests and will submit to the judgement of the CSAB as to whether they should refrain from participation in discussions in which they have an interest. The minutes of CSAB meetings will record whether any interests were declared.