

## Terms of Reference

### FAMCARE – Family Care

*This Terms of Reference (TOR) was approved by FAMCARE on 10/05/2023 and the IPWSO Board of Trustees on 19 July 2023.*

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

**Purpose: The purpose of FAMCARE is to support families and all carers of people with PWS.**

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

1. Compiling relevant and up to date information into easily read articles for all families living with children, adolescents and adults living with PWS with the approval of and distribution through IPWSO.
2. Ensure contribution and review of all information and articles produced by FAMCARE by the FAMCARE Committee member representative from the IPWSO CSAB, prior to the publication of the articles on the IPWSO website, social media, etc.
3. Reviewing and revising materials relevant to the support and care of individuals living with PWS.
4. Responding to queries from IPWSO Trustees or others within IPWSO relating to the support and care of individuals living with PWS.
5. Attending in-person or online conference call meetings to discuss matters relating to supporting families of individuals living with PWS.
6. Contributing to the preparation and hosting of Parent Programmes for the IPWSO Conferences every 3 years.
7. Connecting with family members who may seek personalised assistance, through IPWSO, regarding their relative living with PWS.
8. Supporting the translation of FAMCARE articles into languages that are identified as highly important and relevant to the IPWSO community.

### ***Membership:***

- The membership of FAMCARE comprises parents or family members of people living with PWS and professionals involved in the support of people with PWS.
- The FAMCARE Committee will be made up of at least 6 active members including both family members and professionals.
- If requested by the IPWSO President, FAMCARE 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 FAMCARE.
- FAMCARE will meet online or in person at least 3 times a year.
- FAMCARE members will be eligible to serve a maximum of 3 consecutive 3-year terms, with the exception of FAMCARE members who have served as the FAMCARE Chair. Chairs and former Chairs will be eligible to serve a maximum of 4 consecutive 3-year terms.
- A FAMCARE member who has served 3 consecutive terms may serve one or more additional terms after a gap of at least 1 year.
- FAMCARE 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 FAMCARE is by invitation-only and the membership proposed by FAMCARE will be submitted to the IPWSO Board for consideration and approval in advance of each triennial IPWSO Conference.
- A Chair will be selected by FAMCARE 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 FAMCARE members are expected to uphold the values and pursue the mission of IPWSO.
2. Approval of the IPWSO Board of Trustees shall be secured in advance for any activities performed on behalf of IPWSO or publications produced, which are property of IPWSO.
3. FAMCARE will report to the IPWSO Board of Trustees annually on its previous year's activities and on proposals for the future and on any other matters of relevance to IPWSO.
4. The Chair of FAMCARE or their nominee should where possible attend the IPWSO Board of Trustee meetings and report on the activities of FAMCARE. In the event of

being unable to attend, the Chair or their nominee should update the Board by another means.

5. FAMCARE may submit funding requests to the IPWSO Board of Trustees. If funding is approved, it will be the responsibility of the FAMCARE to ensure that relevant IPWSO policies and procedures, including those relating to financial management and purchasing, are adhered to at all times.
6. FAMCARE will ensure that any projects it oversees for which donor funding has been received is compliant with the terms and conditions of the donor.
7. Members of FAMCARE shall at all times 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.
8. All FAMCARE members are volunteers and any actions performed by FAMCARE should be in the best interest of IPWSO and cannot personally profit any FAMCARE Committee member. Each individual shall disclose to IPWSO and FAMCARE any personal or financial interest which he or she may have in any matter pending before IPWSO or FAMCARE and shall refrain from participation in any discussion and decision on such matter.