

Introduction to IPWSO

The International Prader-Willi Syndrome Organisation (IPWSO) is registered as a charity in England and Wales. It is run by a board of up to 12 Trustees (10 elected and 2 co-opted). At least 50% of elected Trustees are close family members of people with Prader-Willi Syndrome (PWS). IPWSO's governing document is its [Constitution](#). IPWSO's [Strategic Plan](#) sets out its mission and what it hopes to achieve in the coming years.

Responsibilities of Trustees

Trustees have overall control of a charity and are responsible for making sure it is doing what it was set up to do. Trustees are the people who lead the charity and decide how it is run. Being an IPWSO Trustee means making decisions that will impact on the lives of people with PWS and their families around the world. It is expected that all IPWSO Trustees will understand and support its mission.

In England and Wales charities are regulated by the Charity Commission. It sets out [6 main duties](#) that Trustees are required to fulfil:

1. Ensure your charity is carrying out its purposes for the public benefit;
2. Comply with your charity's governing document and the law;
3. Act in your charity's best interests;
4. Manage your charity's resources responsibly;
5. Act with reasonable care and skill;
6. Ensure your charity is accountable.

The role of IPWSO Trustees

IPWSO Trustees meet monthly by Zoom and will be expected to read meeting materials distributed by staff and others in advance. IPWSO Trustees are expected to participate in discussions during Trustee meetings and to respond in a timely fashion to communications issued by email between monthly meetings.

Monthly Trustee meetings currently take place on the last Monday of each month at 8pm London time. Each new Trustee Board will decide a meeting time and dates to suit the majority of participants. Due to the global nature of IPWSO it is inevitable that some people will be required to attend meetings late at night or early in the morning.

Most IPWSO Trustees join one or more IPWSO Committees, which also meet regularly.

- The Fundraising and Finance Committee is responsible for advising the IPWSO President and Trustees on all matters relating to fundraising and finance. This includes oversight of financial planning, ongoing monitoring of IPWSO's finances, and establishing and managing IPWSO's fundraising strategy.
- The Conferences and Workshops Committee, in cooperation with any host organisations, seeks to ensure the efficient and effective organisation, promotion and undertaking of training events, workshops, and conferences in which IPWSO is either the lead organization or where IPWSO is making a significant contribution.
- The Public Policy Committee is responsible for preparing policy statements addressing issues that may be common across different countries, relevant to the care, education, social security, and treatment of people with PWS.
- The Project ECHO Committee oversees the development, implementation and evaluation of IPWSO Project ECHO as a whole and the same for each of the different ECHOs that IPWSO establishes.
- The Website and Publications Committee oversees the improvement and maintenance of IPWSO's image and global profile and the accessibility of its resources through a modern communications and publications strategy including the use of social media and its website.

On average, IPWSO Trustees committed 20 hours per month to IPWSO activities during 2020, although this varied considerably between Trustees. All Trustees are expected to be available for a minimum of 8 hours of IPWSO work per month.

IPWSO Trustees are not paid, although reasonable expenses incurred during the course of essential IPWSO work will be reimbursed.

The working language of IPWSO is English and all Trustees are expected to be able to communicate in written and spoken English.

IPWSO currently has 2 full-time and 2 part-time staff members who carry out much of the day-to-day work of IPWSO. IPWSO's staff team may increase or decrease depending on the availability of funding. IPWSO's most recent accounts are available on its [website](#).

All IPWSO Trustees are required to commit to its Code of Conduct and sign a Register of Interests immediately upon taking office.

The election of IPWSO Trustees

A list of potential IPWSO Trustees is nominated by the IPWSO board and proposed for election at the IPWSO General Assembly, which takes place immediately after each IPWSO Conference. IPWSO members (national PWS association) each have one vote and can vote in favour or against this list.

The term of office for an IPWSO Trustee is 3 years and Trustees may not hold more than 2 consecutive terms.

Applying to become an IPWSO Trustee

To apply to become an IPWSO Trustee please submit the Application Form, a head and shoulders photograph, and a brief biography (250 words or less). You are welcome to also submit a Curriculum Vitae and reference from your national PWS association if you wish.

A Zoom call will then be arranged between you and IPWSO's Nomination Committee, during which your application will be discussed and you will have an opportunity to ask any questions.

If you are nominated by the IPWSO Board, the photograph and brief biography you provide will be posted on the IPWSO website and circulated to IPWSO members in advance of the General Assembly.

Desirable Skills for Trustees

As a global organisation, IPWSO is eager to have Trustees from around the world. For the 2022-2025 term we are particularly keen to attract Trustees from Latin American, Africa and Asia.

We are also particularly interested to hear from candidates who have any of the following and are willing to use them to further IPWSO's mission:

- Fundraising skills or contacts who can support IPWSO's fundraising;
- Fluency in languages in addition to English, particularly languages that are widely spoken;
- Finance, accounting and audit skills;
- Marketing, PR and media skills;
- Governance skills;
- Human resource management skills;
- IT and website management skills;
- Experience of strategic planning.

Why apply to become an IPWSO Trustee?

- IPWSO Trustees help others by using their skills and experience to work in pursuit of IPWSO's vision of a world where people with PWS and their families receive the services and support they need to fulfil their potential and achieve their goals.
- IPWSO Trustees are at the centre of a global network of families and professionals who are committed to supporting people with PWS and their families.
- IPWSO Trustees have an opportunity to learn about needs in different parts of the world as well as emerging research and new treatments.

What IPWSO's retiring Trustees say

There is no doubt that becoming a Trustee of IPWSO entails considerable commitment of time. What is less obvious is the friendships and camaraderie that develops as you reach out to other likeminded families, carers, researchers and health professionals. I feel blessed to have served on the Board of IPWSO and will be retiring with a much deeper understanding of what it means to live with PWS across the globe.

James O'Brien, Australia, IPWSO Trustee from 2016. Due to retire in 2022.

6 years as an IPWSO trustee

It is a great opportunity to be part of a strong network for an ongoing process together with wonderful people – all of them experts - working for a better and easier life for affected people with Prader-Willi-Syndrome: persons with PWS, families, caregivers, health experts...

As a mother with more than 30 years of trying to understand this complex syndrome I learned about the multiple challenges around the world and the motivating moments of finding solutions or at least relieving possibilities.

Of course, active participation is necessary to support as good as you can the engaged, demanding, and successful work of the employed staff.

And - as a German speaking member, I had the opportunity to get used to all the different English global variants and to approve little by little my linguistical knowledge.

All in all, a wonderful enriching experience!

Thank you!

Verena Gutmann, Salzburg, June 2021