

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.

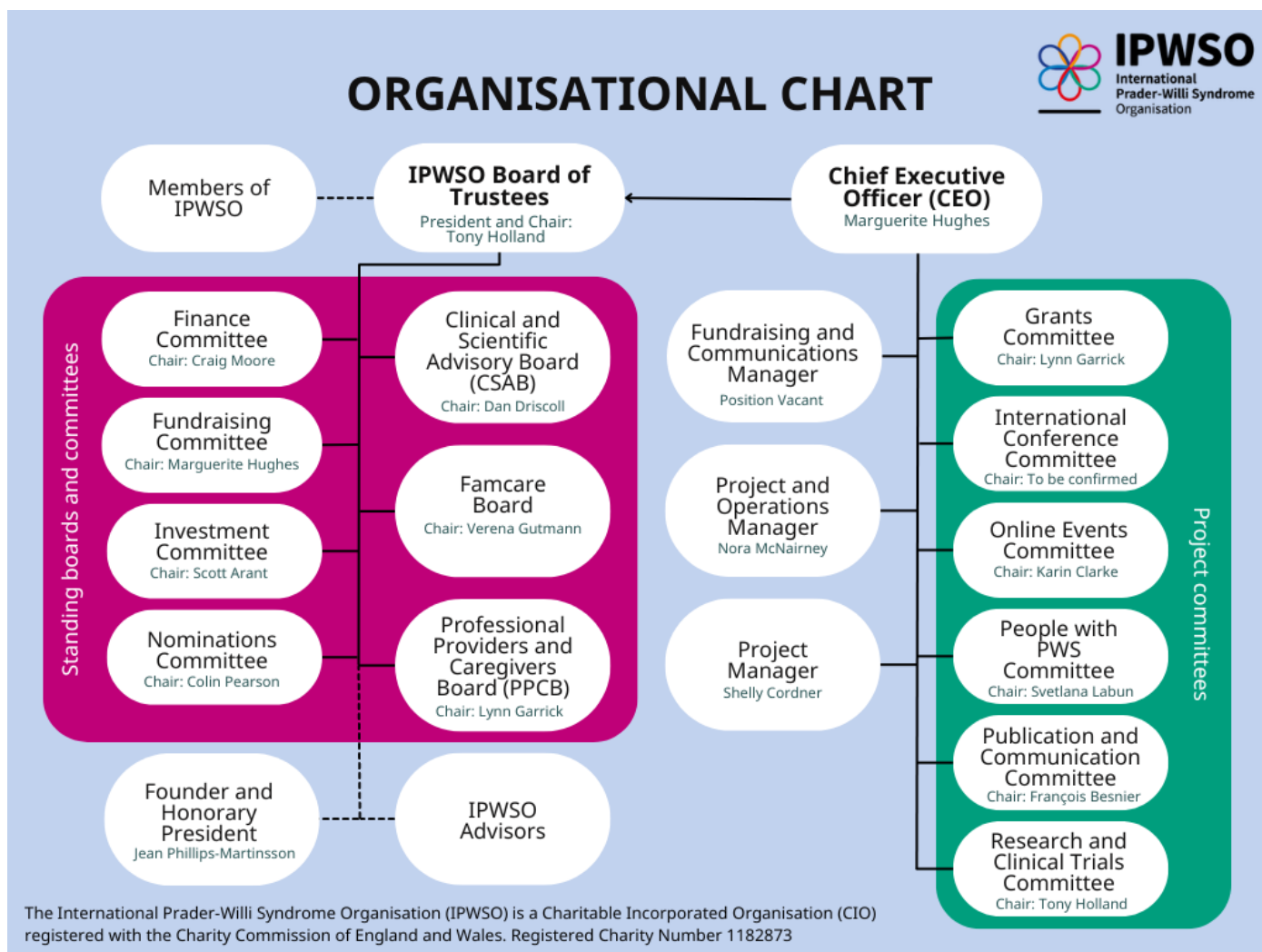
The role of IPWSO Trustees

IPWSO Trustees meet every second month 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 meetings.

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 Trustees also participate in consultation meetings, which are held on the months during which there is no Trustee meeting. Consultation meetings bring together IPWSO volunteers and staff for a discussion on a topic of broad interest to the global PWS community.

Most IPWSO Trustees join one or more IPWSO Committees, which also meet regularly and are listed on IPWSO's organisational chart.



All Trustees are expected to be available for a minimum of 8 hours of IPWSO work per month, although many commit far more time.

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 held at the International PWS Conference in Arizona, USA in June 2025.

Desirable Skills for Trustees

As a global organisation, IPWSO is eager to have Trustees from around the world.

We are 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.

Thoughts from retiring IPWSO Trustees

Being a trustee is both a great honour and a great responsibility. During this journey, I have learned so much about the resources or lack thereof in other areas of the world. Being a trustee has helped me feel like a part of the global PWS family and has allowed me to see how connected we are. I have learned so many things from experts worldwide and am proud to say that being a trustee has allowed me to share knowledge that will help others with PWS and their loved ones for years. Not only do I feel that I have made a difference, but I have also made lasting friendships worldwide. IPWSO is an incredible international organization committed to creating a world where people with PWS and their families receive the services and support they need to fulfill their potential and achieve their goals.

Lynn Garrick, USA, mom to John (18). Trustee from 2019-2025

After more than 20 years active in the French PWF association, I was very excited to join IPWSO in 2019. It has been a great adventure, sharing with families and professionals our difficulties and hopes, and working to build a better life for our children and their families.

Giving access to the variety of situations and cultures all over the world is very challenging and stimulating. Working with health professionals, researchers, caregivers and families forces all of us to question our vision, to invent together new paths, to innovate.

My daughter was born in 1970 and died in 2017. She inspires me and tells me we must never give up and must work to build a better world for all of them.

I will retire in 2025 and will miss the IPWSO family, though I will always be available if needed.

François Besnier, France

As a scientist who had studied PWS for almost 15 years, I applied for and was nominated to become an IPWSO trustee in November 2019. The last 4.5 years have been an incredible learning experience.

I have developed a much better understanding of what it means to live with PWS from a very wide range of perspectives. And I have enjoyed the privilege of working alongside people from many different backgrounds, with interesting ways of thinking and approaching problems, which I have learned a lot from.

The global perspective that comes from working with the IPWSO board is also I think quite a unique experience – with such a unifying and specific common goal, it feels like we can really start to understand and tackle some of the challenges that play out in different ways across cultures.

Kate Anne Woodcock, Reader in Applied Clinical Psychology, University of Birmingham, UK