

# THE INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION



## CHIEF EXECUTIVE OFFICER APPLICATION PACK



[www.ipwso.org](http://www.ipwso.org)

September 2024

# Welcome



On behalf of the Board of Trustees, thank you for your interest in IPWSO. We look forward to exploring with you this exciting opportunity to join us as our new CEO.

IPWSO is committed to creating a world where people with Prader-Willi syndrome (PWS) and their families receive the services and support they need to fulfil their potential and achieve their goals. This is a challenging but immensely rewarding opportunity to lead an organisation that is making a significant impact across the globe.

We are proud of our achievements but there is much to be done!

As a small charity our finances are limited. However, there is no limit to our commitment to providing fulfilling opportunities for the passionate individual who shares our vision.

If you are seeking opportunities for meaningful work, the chance to learn and grow in a dynamic and innovative environment and you want to promote a more equal world, this could be the job for you.

Over the last few years we have invested in our staff team and reviewed our strategic objectives. We are excited about the next stages in our journey as we work to improve life for all those affected by PWS.

Thank you for considering the role of CEO at IPWSO and I look forward to progressing your application.

With kindest regards

A handwritten signature in black ink, appearing to read 'Tony Holland'. The signature is fluid and cursive, written on a light-colored rectangular background.

Tony Holland  
**IPWSO President**

## What is Prader-Willi syndrome?

Prader-Willi syndrome (PWS) is a complex genetic disorder characterised by low muscle tone and failure to thrive at birth, and later evidence of short stature, intellectual disabilities, behavioural and psychiatric challenges, and impaired satiety.

The latter is associated with excessive food intake (hyperphagia) that results in severe obesity, if access to food is not carefully controlled. Where severe obesity is a problem this can lead to additional health problems, such as type 2 diabetes mellitus and sleep apnoea.

Relative growth and sex hormone deficiencies are very common requiring hormone replacement, and monitoring for other health problems is required, such as severe spinal curvature.

Research has shown that between 1 in 15,000 and 30,000 people in the populations studied are born with PWS. PWS occurs across all races and both sexes, although life-expectancy may differ between countries depending on the availability of early diagnosis, information, treatments, services and support.

## About us

We are the international umbrella body for Prader-Willi syndrome (PWS) associations around the world. We were founded in 1991 by a group of parents and professionals to promote better information, support and international co-operation to bring about improvements in the lives of people with Prader-Willi syndrome (PWS). Currently we have 47 full (fee paying) country members and contacts in over 120 countries. We have a staff team of 4 who work in conjunction with dedicated volunteers from around the world.

We are committed to supporting all people with PWS and their families, whatever their needs, and wherever they live.

IPWSO is registered with the Charity Commission for England and Wales.

## Vision and mission

### Our Vision

A world where people with PWS and their families receive the services and support they need to fulfil their potential and achieve their goals.

### Our Mission

To unite the global PWS community to collectively find solutions to the challenges of the syndrome and to support and advocate for people with PWS and their families, PWS associations, and professionals who work with people with PWS.



## Values



**Global Solidarity.** We are committed to working for a more equal world where all people with PWS can achieve their full potential regardless of their economic, geographic or family circumstances.



**Commitment to Science.** We believe that people with PWS and their families deserve clinical care, treatment recommendations, services and support that are based on rigorous empirical research and we will promote scientific reasoning throughout our organisation.



**Collaboration.** Premised on a belief that we can all learn from each other and benefit from each other's work, we are committed to fostering new relationships, willingly supporting others, and working cooperatively with diverse stakeholders in pursuit of common goals.



**Respect for all.** We are committed to equality for all people regardless of their sex, sexual orientation or gender reassignment, their race, colour or religion, their disability, marriage status or age.

## What we do

**We build communities** between people with Prader-Willi syndrome, their families and the professionals who support them in order to share knowledge and expertise and improve outcomes for those affected by the syndrome everywhere in the world.

**We want everyone with Prader-Willi syndrome to get equal access** to diagnosis and treatment. We want better and more consistent outcomes for people with the syndrome and their families no matter where in the world they live.

**We work to ensure research into the syndrome works for everyone** and reflects their diverse experiences and environments.

Visit our [website](#) and read our [2023 Annual Report](#) for further information on our activities, financial position, achievements and future plans.

# Our impact in 2023



100+

Advice line enquiries received from over **100** individuals in **47** countries

45

Members, and contacts in over **120** countries



6979

Volunteer hours

7

Conference grants awarded

6

Small project grants awarded

15

Diagnostic tests provided

409

**409** people attended online meetings, from over **100** countries

4

Travel scholarships awarded

914

Hours of our videos watched on YouTube

5

Educational outreach conference visits



# Job description

## **Main purpose and scope of role**

Working closely with the President and the Board of Trustees, the CEO will provide strategic vision and leadership and will strive to ensure that IPWSO delivers its charitable purposes and remains successful and sustainable.

Duties and Responsibilities (to include but not limited to)

## **Leadership**

- Strive to ensure that the charitable purposes of IPWSO are followed and that it delivers the public benefit set out in its governing document.
- Take overall responsibility for the management and administration of IPWSO.
- Provide support and information to the Board of Trustees to enable trustees to fulfil their roles and legal responsibilities.
- Pursue close cooperation with, and accountability to, IPWSO's members.
- Act as an ambassador for IPWSO by representing IPWSO at events and networking to build new strategic relationships.
- Keep abreast of relevant new research, treatment recommendations and service developments for people with Prader-Willi syndrome.

## **Governance**

- Strive to ensure that IPWSO has governance systems in place that enable it to consistently fulfil its legal, statutory and regulatory responsibilities.
- Maintain awareness of risks and changes in the external environment that could affect IPWSO and advise the Board of Trustees accordingly.
- Together with the President manage complaints (including from whistle-blowers) and recommend actions to the Board of Trustees

## **Finance and Fundraising**

- Work with the Treasurer and the Finance Committee to ensure the overall financial health and sustainability of IPWSO.
- Work with the Treasurer and the Finance Committee to prepare budgets for review by the Board of Trustees and to enable IPWSO to operate within its financial means.
- Seek to ensure that appropriate financial reports are submitted to the Charity Commission and other entities as required.
- Support the work of the Fundraising Committee with particular emphasis on fundraising from corporate and institutional donors.
- Support the Fundraising Manager whose focus is on joint fundraising campaigns with partner organisations and also individual giving.
- Seek to provide high quality support to existing donors, by means including the preparation of regular reports and updates.

## **Staff, Trustee and Volunteer and Committee Support**

- Provide support to staff, trustees and volunteers to enable them to carry out their duties.
- Deputise for other staff members during periods of leave.
- Conduct annual reviews with staff.
- Participate in the recruitment of new staff as required.
- Provide support and advice to IPWSO committees and conference organisers.

## **Project Support**

- Have oversight of all IPWSO projects to ensure they are designed and implemented in accordance with IPWSO's mission and objectives.

# Person specification

## Experience, Knowledge and Skills

### Essential

- Proficiency in English.
- Experience of working in a leadership role in the charitable sector either as a CEO or as part of a wider Senior Management Team.
- Ability to articulate a compelling vision and to inspire others.
- Broad understanding of global development issues, geopolitical dynamics, and cultural nuances and able to take into account the diverse contexts in which IPWSO operates.
- Strategic Thinking: experience of leading and or contributing towards strategic development as well as experience of organisational management and supporting change.
- Collaborative approach: Outstanding interpersonal and communication skills, with the ability to build and maintain positive relationships, based on mutual respect and shared goals.
- Experience of managing budgets, financial planning, preparation of funding applications and report writing.
- Experience of working with volunteers.

### Desirable

- Fluency in another language.
- Experience of working in a leadership role in an international nonprofit organisation within health or disability either as a CEO or as part of a wider Senior Management Team.
- Knowledge/experience of PWS.
- Willingness to travel internationally as needed to support IPWSO's priorities.
- An understanding of charity operations and governance structures in the UK.

## Personal Attributes

### Essential

- Enthusiasm for IPWSO's work and commitment to its vision, mission and values including dedication to equity, diversity, and inclusion.
- Empathy for disadvantaged people.
- Cultural sensitivity and respect. Confidence and ability to work well with people from different backgrounds from around the world.
- Highly self-motivated and able to work on own initiative as well as part of a team.
- Adaptability and Flexibility. Able to navigate change and uncertainty. Able to accommodate international times zones as well as GMT for UK based staff. 20% of time may be outside of normal working hours.
- Ethical leadership
- Resilience and determination

### Desirable

- Desire to empower and mentor staff and foster a culture of learning, growth, and innovation.

# Terms of appointment

- Contract:** 2 year contract with a view to renewal thereafter.
- Salary:** The salary for this position will vary depending on the country of the successful candidate. We offer a competitive salary range, adjusted according to the local cost of living and market standards. We are committed to providing a fair and competitive compensation and adhere to local legal requirements.
- Hours:** 20 hours per week. Working hours are flexible. 20% of the time may be outside of normal working hours to facilitate evening meetings. As the current staff at IPWSO are UK based, there is an expectation that the CEO will be accessible during GMT.
- Location:** Home based
- Pension:** 5% employer contribution
- Annual Leave:** 35 days pro-rata during each holiday year (January-December) including bank holiday entitlements in the country of residence. The full time working week is 37.5 hours.

# How to apply

Submit your CV with a covering letter, of no more than two A4 pages, describing how you meet the requirements of the role and the criteria outlined in the person specification. Include in your covering letter the names, positions, organisations, email, and telephone contact numbers of two referees, one of whom should be your current/most recent employer. References will only be sought once your express permission has been granted.

Please send to: [nmcnairney@ipwso.org](mailto:nmcnairney@ipwso.org). The closing date for applications is **9.00 AM (UK time) on 25 October 2024**.





## Support IPWSO

- Please [donate](#)
- Join our [mailing list](#)
- Connect with us on [Facebook](#), [Twitter](#), [Instagram](#), [YouTube](#) and [LinkedIn](#)

IPWSO is registered as a charity in England and Wales, charity no. 1182873.