

THE INTERNATIONAL PRADER-WILLI SYNDROME ORGANISATION



CHIEF EXECUTIVE OFFICER APPLICATION PACK



www.ipwso.org

January 2026



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, reading "N. Finan". The signature is stylized and cursive.

Nick Finan
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 [2024 Annual Report](#) for further information on our activities, financial position, achievements and future plans.

Our impact in 2024



100+

Advice line enquiries received from over **100** individuals in **40** countries

47

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



7199

Volunteer hours

9

Conference grants awarded

10

Small project grants awarded

17

Diagnostic tests provided

137

137 people attended online meetings

10

Travel scholarships awarded

20,864

YouTube views

4

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 ensure that IPWSO delivers its charitable purposes and remains successful and sustainable.

Duties and Responsibilities (to include but not limited to)

Leadership

- Ensure that the charitable purposes of IPWSO are followed and that it delivers the public benefit set out in its governing document.
- Lead and manage IPWSO's business, including communicating priorities, developing and implementing operational plans in accordance with statutory and regulatory obligations.
- Provide support and information to the Board of Trustees to enable trustees to fulfil their roles and legal responsibilities.
- Develop and foster strong strategic relationships with a range of stakeholders across the corporate, government, non-profit and community sectors, including families, IPWSO members and other disability groups.
- Be IPWSO's ambassador and meaningful voice in the community and engage effectively with external stakeholders including media.
- Keep abreast of relevant new research, treatment recommendations and service developments for people with Prader-Willi syndrome.

Governance

- Ensure that IPWSO has governance systems in place that enable it to consistently fulfil its UK 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

- Together with the Project and Operations Manager, work with the Treasurer and the Finance Committee to ensure IPWSO's financial health and sustainability, preparing budgets and ensuring 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 work of the Communications and Engagement Officer with digital fundraising campaigns and ways to increase individual giving.
- Together with the Project and Operations Manager 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.
- Conduct the duties of 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.
- Provide administrative support to the Clinical and Scientific Advisory Board (CSAB), the Fundraising Committee, and the Research and Clinical Trials Committee.
- Co-ordinate the "Ask a Professional" component of the IPWSO Advice Line.

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 if needed in order 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:** 25 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, high-speed internet and fully equipped office, a must.
- Pension:** 5% employer contribution
- Annual Leave:** You are entitled to the equivalent of 7 week's annual holiday each year (35 days between January and December), including all UK bank holiday entitlements, calculated on a pro rata basis (37.5 hours per week is equivalent to a full time working week).

How to apply

Apply on the Charity Job website and submit a copy of your CV with a covering letter of no more than two pages of A4, 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.

We will be reviewing applications and interviewing applicants on a rolling basis. We encourage you to apply early, as the advertisement may close before the date specified below if a suitable candidate is found. If you have any queries please contact Nora McNairney - nmcnairney@ipwso.org.

The closing date for the receipt of applications is 19 February 2026 at 5 pm UK time.



Support IPWSO

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

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