

IAPO Governing Board Nomination Form 2022

Please complete this Nomination Form and return to IAPO by email to AGM2022@iapo.org.uk. The deadline to receive nominations is **Saturday 29 January 2022 at 23:59 GMT**. The Nominations Committee will assess all the applications and the information about the shortlisted candidates will be provided to all IAPO Members in the Governing Board Nominations Booklet (GBNB) that will follow. GBNB will have a summary matrix which will outline the details provided by you in questions 1-5 below about your participation and engagement within IAPO membership and activities, your regional and international advocacy, your advocacy skills, experience, disease area and country information of the nominees. **Please note that each section has a word limit and that, to be fair to all nominees, any text over this word count will NOT be included in the nominations booklet.**

Please note that, under the law of England and Wales some people are disqualified from acting as trustees. You cannot be a trustee if you: have an unspent conviction for an offence involving dishonesty or deception; are currently declared bankrupt, subject to bankruptcy restrictions or an interim order have an individual voluntary arrangement to pay off debts with creditors; are disqualified from being a company director or have previously been removed as a trustee by either the Charity Commission or the high court due to misconduct or mismanagement

Your name: Tony Holland

Your member organization: International Prader-Willi Syndrome Organisation (IPWSO)

Your position at the member organization: President

Your email address: tonyipwso@gmail.com

Please write a short biography or CV here, including information about your experience with patients' organizations and other health-related institutions, such as on boards or committees at the international, regional or national level (maximum 600 characters).

Until retirement I was an academic psychiatrist in the Department of Psychiatry, Cambridge University, also working in the UK NHS. I have been Chair of Trustees of the International Prader-Willi Syndrome Organisation since 2016, overseeing substantial change, obtaining charity status in the UK. I have been adviser to the Royal College of Psychiatrists, Down Syndrome Association (UK), Down Syndrome International, Prader-Willi Syndrome Association UK and the International Association for the Scientific Study of Intellectual Disabilities. In 2010 I was elected to the Academy of Medical Sciences and in 2015 I was awarded the Commander of the British Empire (CBE) for services to Psychiatry.

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Requirements and commitments of Governing Board members

(Please tick to show you meet these requirements and accept these commitments)

- Ability to use English as a working language, both verbal and written. Or have an interpreter to support you throughout your entire mandate at the Governing Board.
- COVID19 restrictions permitting, to attend UP TO two face-to-face/ Virtual meetings of the Governing Board per year (expenses reimbursed).
IAPO's travel policy is that it will cover the cost of economy travel (by air, train or other methods) for board members. IAPO aims to meet the needs of those with medical conditions which require specific travel needs and support on request. Please ask for further details. Due to the COVID-19 pandemic, face-to-face meetings will be decided as per prevailing government and WHO advisories.
- To attend one Zoom meeting of the Governing Board per month.
- To be available for conference calls, telephone and email communications between these meetings, both with other Governing Board Members and with IAPO staff as necessary.
- To be prepared to commit a minimum of one hour (on average) per week to IAPO.
- To ensure that your organization is in good standing and its membership fees were up to date to 31st December 2019 when the COVID19 special fee waiver was applied.
- Previous experience on boards or committees at the international, regional or national level.
- Understanding and experience of governance within a non-profit organization.

UK Applicant Only (Special Conditions¹)

- I meet the conditions listed in the Footnote: Citizenship, Address, Phone, UK Bank Account

Please answer the questions below.

1. What IAPO activities did you engage in since your membership of IAPO? (Please tick all that apply and provide details below. You can also provide links, e.g. social media or website).

- Attended AGM and Committee meetings - Which meeting have you attended? What was your role in the meeting?
- IAPO Strategy Consultation - Which consultation?
- IAPO Global Patients Congress - Which Congress and what was your role: speaker, moderator, poster exhibitor, other?
- IAPO Regional Meeting (Asia Pacific, Africa, LatAm, etc) - Which have you attended? What was your role in the meeting?
- IAPO Social Media Campaign - Which and what did you do?
- Patient Solidarity Day - How have you marked the day?
- WHA and WHO Regional Committees - Which meeting?
- External Policy Consultation - Which consultation?
- Publications/research/advisory boards at a national or regional level
- Other - Describe below.

¹ As per the requirements of the UK Charity Commission and the UK banking rules, at AGM 2022 IAPO needs to elect one board member with UK Citizenship, who has a UK bank account, proof of address, and a UK registered mobile phone.

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Please use this space to give details of IAPO activities you engaged in since your membership of IAPO and your role in the activity (maximum 900 characters).

IPWSO is a proud member of IAPO and colleagues have recently attended the following IAPO events of which I have been briefed. In particular, I have been a core member of IPWSO's Project ECHO team, which our Vice-President James O'Brien presented on at your Asia-Pacific event.

3rd Asia Pacific Patients Congress
1st African Patients Congress (APC 2021)
9th Global Patients Congress

2. What regional or international health or patient advocacy activity did you take part in over the last two years? (Please tick all that apply and provide details below. You can also provide links, e.g. social media or website).

- WHO frameworks and other consultations - Which ones?
- World Bank and other Bodies consultations - Which ones?
- WHO regional advocacy - Where and what issues?
- Other - Describe below.

Please use this space to give details of your participation in regional and international advocacy over the last 2 years (maximum 600 characters).

As Chair of IPWSO our remit is to advocate on behalf of our members to improve the lives of people with PWS, extend knowledge and provide access to diagnosis. This work includes representing the organisation at global conferences and meetings.

Through IPWSO I have been involved in the RDI / Eurordis campaign to lobby the UN to adopt the Resolution on "Addressing the Challenges of Persons Living with a Rare Disease and their Families."

I have also been involved in their campaign on Universal Health Coverage and have promoted this through the work of IPWSO.

On behalf of IPWSO I am leading a global initiative of parents and professionals to improve understanding of the mental health needs of people with PWS.

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3. What particular skills or expertise could you bring to IAPO's Governing Board? (Please tick all that apply and provide details below. You can also provide links, e.g. social media or website)

- Advocacy and policy, such as expertise on particular policy issues of relevance to patients or of a particular policy-related organization (e.g. WHO, PAHO, EU and UN etc)
- Communications, such as strategy, media, identity, communicating key messages
- Financial, such as accountancy, strategy, financial planning or management
- Fundraising, such as corporate and foundation fundraising, writing funding applications
- Legal skills
- Public speaking skills
- Membership, such as providing membership services and support
- Organizational development and strategic planning
- Training, such as running workshops or producing written training/capacity building materials

Please use this space to give details of particular skills you would like to bring to IAPO's Governing Board and how these can contribute to IAPO carrying out its mission today and into the future. You may want to include examples of previous experiences or achievements in these areas (maximum 600 characters).

Advocacy and policy: advocacy roles - Royal College of Psychiatrists, DSA UK, PWSA UK and IPWSO. I have an interest in learning disability and rare diseases advocating on these issues at academic events and in articles.

Public speaking skills: experienced at public speaking having spoken at conferences around the world and in media interviews. I understand the need for organisations to be able to present their work in a clear and concise manner.

Organizational development and strategic planning: chaired IPWSO through organisational change, applying for UK charity status, moving to a UK base, opening UK bank accounts, overseeing changes to the constitution and the introduction of strategic planning.

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4. What do you see as the opportunities for IAPO's role promoting patient-centred healthcare in the next 5 years? How do you see IAPO's role in helping the world recover from the COVID-19 pandemic and build back better?

(Please keep your answer to no more than 900 characters).

The pandemic has clearly had a huge impact on healthcare as well as on the ways people work, the speed at which interventions can be rolled out and the use of technology to support remote access to information. At IPWSO I have experienced the benefits of the IPWSO ECHO project, which aims to develop communities of good practice around the world, for example, reaching people in disparate locations and linking them up to share important healthcare information.

Representing organisation addressing very different health conditions, IAPO is in a good position to develop an understanding of the strengths and risks associated with healthcare developments, such as ECHO programmes and Telehealth. As the world recovers from the pandemic decisions will have to be made by Governments on future healthcare and particularly technological solutions. IAPO could promote and share best practice globally as well as having a perspective on the regional, financial, and cultural differences that also impact on the nature of healthcare delivery in any given country.

5. Please give details of your involvement and collaboration with other IAPO members to date.

(Please keep your answer to no more than 600 characters. You can also provide links, e.g. social media or website).

IPWSO has a MOU in place with Rare Disease Ghana Initiative to promote our diagnosis service, and I presented at a webinar they hosted on PWS in 2021.

Please note, appointment as a Governing Board member for IAPO requires commitment to IAPO's mission and vision, the acceptance of UK charity and company regulations and good practice for boards of trustees of a charity and an understanding that serving as a Board member is not for personal gain nor for the gain of the nominating organization. The Board member commits to acting in the best interests of IAPO and its membership.

Your nomination

I confirm that the governing body of my organization has approved my nomination as a candidate to IAPO's Governing Board (please attach document)

I have read the IAPO By-Laws and Memorandum and Articles of Association and I am committed to the vision and mission of IAPO and agree to uphold IAPO's policies if I am elected to the Governing Board.

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International Alliance of
Patients' Organizations

A global voice for patients

A handwritten signature in black ink, appearing to be 'M. J. ...', written over a horizontal line.

Signature

28/01/22

Date