

IAPO Governing Board Nomination Form 2020

Please complete this Nomination Form and return to IAPO by email to AGM2020@iapo.org.uk. The deadline for IAPO to receive nominations is **Sunday 14 November 2020 23:59 GMT**. The Nominations Committee will sit and assess all the applications and the assessed information about the 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 nomination 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: Bisi Bright

Your member organization: LiveWell Initiative LWI

Your position at the member organization: 1st Vice Chairman / CEO

Your email address: bisibright@livewellng.org

About you

Please write a short biography or CV below, 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 100 words).

Bisi Bright is a Consultant Clinical Pharmacist, Lecturer and Public Health Manager. She is 1st Vice Chairman and CEO of LiveWell Initiative LWI, a self-sustaining nonprofit healthcare organisation which has impacted almost 2 million nigerian patients.

Bisi is very passionate about patient care and advocacy. She is a very active member of IAPO, having served as a Regional Steering Committee Member of IAPO Africa and, having worked with several patients across the spectrum of care.

Bisi is Deputy National Coordinator of the National Hepatitis Coalition in Nigeria, and a two-time International Award winner of the IATDM/CT and other awards.

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.

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- ✓ To attend two face-to-face 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 are currently suspended.
- ✓ 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 two hours (on average) per week to IAPO.
- ✓ To ensure that your organization is in good standing and its membership fees are up to date.
- ✓ Previous experience on boards or committees at the international, regional or national level.
- ✓ Understanding and experience of governance within a non-profit organization.

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?
 - i) Attended AGM in UK by Proxy representation, Dr Suzanne Tairu of LiveWell Initiative LWI
 - ii) Attended Conference Planning Committee Meetings for the GPC2020 Global Patients' Congress
- IAPO Strategy Consultation - Which consultation?
- ✓ IAPO Global Patients Congress - Which Congress and what was your role: speaker, moderator, poster exhibitor, other? Attended GPC2020 – Played a role as Moderator at 2 Sessions. Mental Health Session and Pharmacy Session.
- ✓ IAPO Regional Meeting (Asia Pacific, LatAm, Africa, etc) - Which have you attended? What was your role in the meeting? Attended the Africa Regional Meeting 2013 in Johannesburg, South Africa. Role Played; Speaker – Delivered a paper titled "Safe Medicines and Safety of Medicines"
- IAPO Social Media Campaign- Which and what did you do?
- ✓ Patient Solidarity Day-How have you marked the day? YES, WE HAVE MARKED MOST PSD days for most years since its inception.
 - i) WINNER OF THE FIRST PSD IAPO PHOTOCONTEST with a photo titled "TRIPLETS" at first Patient Solidarity Day 2013
 - ii) Marked every Patient Solidarity Day from 2013 to 2018
 - iii) See our Patient Solidarity Day Activities at www.livewellng.org also view this page: <https://www.livewellng.org/tag/patient-solidarity-day/>
- ✓ WHA and WHO Regional Committees - Which meeting? Yes, attended WHO Regional Meeting for Africa in September 2020
- External Policy Consultation-Which consultation?
- ✓ Other- Describe below.
 - i) Served on the FIP Workgroup on '**Patients as Partners**', a WHO-IAPO-FIP Initiative which led to the theme 'Nothing for Us without us'

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- ii) **Global Changemaker in Hepatitis C 2017 HONOREE**, By the EIU (Economist Intelligence Unit) for work done in improving patient outcomes in Hepatitis C
- iii) Won an **International Health and Safety Award** in December 2015
- iv) **Commendation letter from the Presidency, Federal Republic of Nigeria**, in October 2017 for recognition of work done in Hepatitis Awareness, Advocacy, Screening, and Linkages of Patients to Treatment and Care
- v) **World Patient Safety Day WPSD2020 Activities**
 - IPC (Infection Prevention and Control) Training with theme "Safety First"; for promoting the Safety of Healthcare Workers in the era of COVID-19; a programme run at the Wellness Auditorium, Gbagada Lagos Nigeria
 - Active participation in the WPSD Symposia and Activities at GPCS2020
 - Moderation of Session on Patient Safety and Medicines at the GPC2020 Global Pharmacy FIP Session.

Please use the space below to give details of IAPO activities you engaged in since your membership of IAPO and your role in the activity (maximum 150 words).

IAPO ACTIVITIES:

Since our membership of IAPO, I have actively engaged in several activities to boost patient outcomes.

Among these activities are at this link:

<http://www.livewellng.org/?s=patient+solidarity+day>

We have:

- Annually marking the Patient Solidarity Day PSD 2013 since its inception, for the first five years, at our own cost. We were able to attend to nearly 6000 women and children in 4 days of travel-outreaches and the communities were enthused and impacted. We won the IAPO PHOTOCONTEST that year.
- We marked the Patient Solidarity Day 2014 with a FISH FESTIVAL PARTNERSHIP with Lagos State Government where we attended to patients from all walks of life, and several members of the general public, many of whom were not aware of their concomitant health conditions and latent illnesses like Hypertension, Diabetes, etc...We gave them all free healthcare and free medicines and enrolled the sick ones on our Home Healthcare Project, easyhealth.

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? i) UN HLM Meeting in New York, September 2019; ii) SDG Zone, September 2019, iii) Post-HLM Strategic Session on UHC 2030, New York, September 2019 – Universal Health Coverage

World Bank and other Bodies consultations- Which ones? IFC Women Leaders in Healthcare Forum , October 2020

WHO regional advocacy- Where and what issues?

Other- Describe below. i) Member, UN Global Compact in good standing October 2015-date ii) We pursue SDGs 1,3,4,5,6 and 17. We are concentrating on Poverty Alleviation (SDG 1) through our IPAP (Illness Poverty Alleviation Programme) and Health Access for All (SDG3) through ur Community and

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Corporate HealthCare Programmes designed for targeted Patient Groups, to empower them and improve on their health iii) Our Gender Health and Infectious Disease Programme , the Women in Hepatitis Africa, has helped many women and their families to gain good health, preventing and treating hepatitis through our algorithms with qualified Hepatologists on the team.

Please use the space below to give details of your participation in regional and international advocacy over the last 2 years (maximum 100 words).

AFRICAN CONTINENT:

Our Regional Advocacy with Women has trained over 4,000 women from 18 African countries as Hepatitis Champions with resultant

- empowerment of women,
- early detection of hepatitis
- prevention of maternal to child transmission
- early linkages to treatment and care

In 2019, in South Africa where LiveWell Initiative LWI demonstrated rapid diagnostic testing methods for early detection of viral hepatitis in partnership with AASLD

GLOBAL ADVOCACY WORK:

The most recent was our 'MEET AND GREET' Programme which we held in New York City on November 4th 2018 for Womens Health, held by Women in Hepatitis Africa WIHA, led by me.

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)

<https://www.unglobalcompact.org/what-is-gc/participants/70141-LiveWell-Initiative-LWI>

Communications, such as strategy, media, identity, communicating key messages @L_W_I

@WIHA_NG @WIHA_NG2

Financial, such as accountancy, strategy, financial planning or management

Fundraising, such as corporate and foundation fundraising, writing funding applications

Legal skills

Public speaking skills https://www.youtube.com/watch?v=ZP1iWVJJ_sA

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

<http://www.livewellng.org/category/lwi-academy-lwia-trainings/>

Please use the space below 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 100 words).

COMMUNICATION SKILLS, NETWORKING: Among the skills I would like to bring to IAPO's Governing Board are Communications, Networking and Grassroot Skills with winning outcomes.

In addition, my 'People Skills' enables me to 'reach' people.

BARTERS: By creating shared value, we can enhance the spectrum of collaborations. Barter is a tool which I intend to bring into the board, to help broaden the 'scope and reach' of IAPO Board.

MENTORING: For a continent like Africa, I wish to suggest that IAPO Members can be mentors to other members.

MENTORING: Each new member organisation should have a member-organisation mentoring it.
Thank you.

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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 150 words).

PROMOTING PATIENT-CENTERED HEALTHCARE: IAPO has to ensure that Patients are empowered continually. Healthcare Teams around the world must see the patient as a client who is 'always right' and whose 'best interest must always be protected'.

The IAPO Mantra of "Nothing for Us without Us" must be promoted at all IAPO Events and should be encouraged to be adopted as theme and subthemes in Medical and Health Conferences around the world, with Expert Patients taking part as Facilitators.

RECOVERING FROM THE COVID-19 PANDEMIC AND BUILDING BACK BETTER: The Recovery Path for COVID-19 seems a long trail; however, with enhanced IPC Training (Infection Prevention and Control) and adherence to Personal Hygiene by Patients and by All, the end of the road to COVID-19 will be nearer than we thought. To build back better, we must build back discipline and adherence first.

IAPO can organise webinars on Resilience and Building Back better.

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

LiveWell Initiative LWI has been involved with other IAPO Members from the onset and with some, till now.

Among these are:

- Dickson - Epilepsy Support Association (ESAU) epilepsy.org.ug
- Obatunde Oladapo - Executive Director at PLAN Health Advocacy and Development Foundation 2012
- Nana Yaa Agyeman - founder Sharecare Ghana, for immune disorders
- Tendayi Westerhoff – HIV/AIDS Advocate, Zimbabwe
- Regina Kamoga – Country Manager, CHAIN Uganda
- PHANGO
- Zane Wilson / Elizabeth Mutare – SADAG Anxiety.co.za
- Ellos Lodzeni - Patron and Founder Trustee of Patient and Community Welfare Foundation of Malawi
- Theobald Owusu-Ansah – Hepatitis B Foundation of Ghana
- Kenneth Kabagambe – National Organisation of People living with Hepatitis B, Uganda

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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.

✓ I have read the [IAPO's Updated By-Laws](#), [Election Code](#) 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.



12th November, 2020

Signature

Date

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Your name: Buluba Florence

Your member organization: National Community of women living with HIV in Uganda (NACWOLA)

Your position at the member organization: Executive Director

Your email address: fbuluba23@gmail .com

About you

Please write a short biography or CV below, 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 100 words).

Buluba Florence, a Social scientist with over 20 years experience in Public Health and Management. I hold Master degree in Public Administration and Management from Makerere University Kampala Uganda with additional academic attributes from Regional and International Institutions. Currently, an Executive Director of NACWOLA, a Board Chairperson of Alliance of women advocating for Change (AWAC) whose objective is to promote access to health and human rights services among female sex workers. I have **Leadership and Systems Thinking Skills** incorporating Organisational ethical standards, creating opportunities among public health, ensuring continuous quality improvement; and advocating for the role of governmental public health.

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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).

1. At a National level, I belong to a Health Advocacy platform, ie RMNCAH+N that engages with policy makers in advocating for Implementation of public health policies during COVID 19 pandemic' [Anglais et français]PART II
2. I am a Commissioner and Board member in Uganda AIDS Commission (UAC) representing the voices of people living with HIV/TB to ensure policies affecting PLHA in country are recognized and implemented
3. I am a Chairperson COVID -19 TB response, Women Empowerment in the refugee hosting districts of West Nile region of Uganda. The purpose is to empower women and girls with advocacy skills that enhance their ability to demand for access to HIV/TB treatment, influence spouses in seeking TB and other health services

Attended AGM and Committee meetings - Which meeting have you attended? What was your role in the meeting?

- As a Vice Chair Person the Board of Directors at AWAC I have been standing in for the Chairperson to provide guidance on organisational work . Secondly as the Executive Director of NACWOLA and Secretary to the Board , my role has been coordinating members networks for the AGM , working with the Chairperson of the Board in drawing up the Agenda, organising all

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necessary documents including previous minutes for the meeting sending out invitation letters to key stakeholders and ensuring the venue and other logistics are ready for the AGM.

✓ IAPO Strategy Consultation - Which consultation?

1. I Participated in the IAPO African Regional Meeting held in Entebbe, Uganda from, 4th to 5th July 2017 that led to the formation of a Statement emphasizing 'access to safe, effective, quality, affordable and timely medicines that meet internationally-recognized standards, in line with the Sustainable Development Goal 3.8's commitment to "leave no-one behind";
2. Participated in the 9th Global patients Congress. NACWOLA's role was to share and network with IAPO network members, Health Service providers Donors including IAPO secretariat, strategies to be undertaken in developing patient-centred healthcare systems at all levels.

✓ IAPO Global Patients Congress - Which Congress and what was your role: speaker, moderator, poster exhibitor, other?

I participated in the Entebbe Congress meeting 2017 and the 9th Global Patients Congress 2020. My role in Entebbe was to contribute to the formation of a Statement that emphasized 'Recognizing the need for all patients in Africa to have access to safe, effective, quality, affordable and timely medicines in line with internationally-recognized standards, the Sustainable Development Goal 3.8's commitment to "leave no-one behind"; While at the 9th patients Congress, I was a poster exhibitor.

✓ IAPO Regional Meeting (Asia Pacific, LatAm, Africa, etc) - Which have you attended? What was your role in the meeting?

I Participated in the 9th IAPO Global Conference. Sharing information, presented a GPC 2020 Poster on NACWOLA and learning patient centered approaches engaging patients as key stakeholder, and calling upon policy makers to ensure accessibility of affordable quality medicines to patients.

✓ IAPO Social Media Campaign- Which and what did you do?

I Shared IAPO documents from the 9th Global Congress with NACWOLA Board of Directors for information, the Civil Society Health Advocates Platform to learn new ideas. The Platform engaged the local media in advocating for Patient Centered approach of Managing patients in the country. The approach is being practiced and the Government launched a National Community engagement Strategy (CES) to respond to the COVID-19 infections.

✓ Patient Solidarity Day-How have you marked the day?

NACWOLA will join the country in honouring patients Day, share and highlight patient's needs as paramount, organise a dialogue with key stakeholders for necessary action. Engage patients in

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counselling, sensitising patients against stigma and Discrimination. The patient's day is assumed to contribute to improved quality of service and health for the patients.

- ✓ WHA and WHO Regional Committees - Which meeting?

I am a Health Advocate for the Global Financing Facility (GFF) that focuses on *Every Woman Every Child Global Strategy* (2016-2030) to "end preventable maternal and child deaths and improve the health and quality of life of women, children and adolescents by 2030". The GFF aims to close the global financing gap by increasing the available domestic, external, and private sector financial resources that are allocated to Reproductive Maternal Neonatal Child Health (RMNCAH-N.) It is a platform intended to bring together stakeholders in RMNCAH-N from all different parts of society. It does so at international and national level.

- ✓ **External Policy Consultation-Which consultation?**

I attended and Participated in **the International AIDS Conference (IAS) the premier global platform to advance the HIV response.** As the world's largest conference on HIV and AIDS, it sits uniquely at the intersection of science, advocacy and human rights, bringing together scientists, policy makers, healthcare professionals, people living with HIV, funders, media and community. The conference that started in 1985, continues to serve as an opportunity to strengthen policies and programmes that ensure an evidence-based response to HIV and related epidemics.

- ✓ **Other- Describe below.**

At the organisation level my role has been to ensure the organisation's Mission and Objectives are achieved. I represent the organisation at Policy levels, Advocate for the improvement of the quality of health for members through access to treatment, prevention of infections, Network with the Ministry of Health for increased supply of free ART to members. I have been monitoring the Counselling activities at health facilities by NACWOLA members.

Please use the space below to give details of IAPO activities you engaged in since your membership of IAPO and your role in the activity (maximum 150 words).

NACWOLA is a national network that aims at coordinating network organisations towards advocacy for improved health. Since my engagement with IAPO, I have adopted a patient-centred approach aiming at mobilising network organisations and building partnerships, towards joint advocacy on behalf of patients. The advocacy that is currently being used is about engaging Communities at all levels to address prevention, monitor availability of medicines at health facilities. I mobilise and mentor groups of HIV positive women and girls in the refugee hosting districts of West Nile in Uganda. A strategy to engage men in TB prevention and treatment has been adopted. My role has been to build the Capacity of the women to be empowered with economic skills to improve income and access to health services. I am carrying out Research on Patient access to health services, Data collected and analysed will inform policy.

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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 the space below to give details of your participation in regional and international advocacy over the last 2 years (maximum 100 words).

At the International level I have been a member of the Advocates for Access to High – Impact Prevention (AVAC). A Consortium comprised of treatment activists aiming at revolutionizing the care of people living with HIV around the world. As a member, the operations of the group work through strategic, uncompromising, ambitious campaigns, activists lobbying to secure funding for and access to prevention tools like ART for people living with HIV/AIDS. For the last two years I have been part of the CROI conference on Retroviruses and opportunistic infections., an annual conference that aims at providing a forum for researchers.

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

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Assessment Skills focusing on identifying and understanding data, turning data into information for action, assessing needs to address community health needs, developing community health assessments, for evidence based decision making.. **Policy Development/Program Planning Skills** focusing on determining needed policies and programs; advocating for policies and programs; planning, implementing, evaluating policies and programs; developing and implementing strategies for continuous quality improvement; developing and implementing community health improvement plans and Strategic Plans. **Communication Skills** focus on assessing and addressing population literacy; soliciting and using community input; communicating data and information; facilitating communications; and communicating the roles of government, health care, and others.

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 150 words).

IAPO needs a commitment to education and training of patients and healthcare professionals. Patients are experts on their lives and their input is valid. IAPO's overall goal for the next 5 years should focus on Universal health coverage for all , carry out research to inform the effective model that should apply for patient input. Promote patient's involvement from the start of the process, rather than at the end of a project to review the outcomes. IAPO's role should focus on working through networking and community involvement in decision making enhance communication, flexibility, and ability to pull together patient's ideas expertise, improves relations ships and minimises work in silos. IAPO should creates partnerships that include stakeholders, line Ministries, Gender and Economic Development Health service providers in addressing patient's /clients Social Economic and Health needs including Human Rights .

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

(Please keep your answer to no more than 100 words. You can also provide links, e.g. social media or website).

My collaboration with other organisations has been through Networking, sharing advocacy challenges, about patients enhancing flow and access to information about programs developing ideas jointly for specific outcome. For example, NACWOLA and the Human Rights organisations in Uganda networked using International Declarations on Human Rights to advocate against the controversial Bill on HIV Prevention and control in 2019 in Uganda. Another method of working, has been through formation of Consortiums to deliberate on identified health challenges that need attention .NACWOLA and other health organisation has formed a Strategic Alliance in addressing Reproductive health challenges for the Adolescents that is ongoing.

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I have read the [IAPO's Updated By-Laws](#), [Election Code](#) 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.



Signature

14/11/2020

Date

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Your name: Liliana Tieri

Your member organization: Asociación para el Cuidado de la Diabetes en Argentina CUI.D.AR
(Association for the Care of Diabetes in Argentina CUI.D.AR)

Your position at the member organization: Founder and Executive Director

Your email address: lilianatieri@cuidar.org

About you

Please write a short biography or CV below, 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 100 words).

I have 20 years of experience in the social health sector. I'm a tireless fighter who works to improve the quality of attention and care, accessibility and quality of life of people with diabetes, getting involved in the processes that make public policies, to transform them into solid, inclusive, equitable and effective policies for people with diabetes.

In 2001 I founded CUI.D.AR, a non-profit NGO that works for children, youth and adults living with diabetes to minimize the impact of this chronic condition on their lives.

I'm a Member of the National Diabetes Advisory Commission of the Ministry of Health of Argentina and of the Global Network "Blue Circle Voices" of the International Diabetes Federation.

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- Previous experience on boards or committees at the international, regional or national level.
- Understanding and experience of governance within a non-profit organization.

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, LatAm, Africa, 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?
- Other- Describe below.

Please use the space below to give details of IAPO activities you engaged in since your membership of IAPO and your role in the activity (maximum 150 words).

We are IAPO Members since 2018 and I engaged in:

- AGM in GPC 2018 (Miami)
- In 2020, I participated in the Survey that IAPO sent to all its members in order to contribute to have a great impact on its plans to reshape its member engagement strategy
- 9th GPC 2020. We presented a poster about our project "Consultations to patients" to know the real situation in terms of lack of supplies and medication during COVID-19.
- On the website that we specially designed because of COVID, we spread IAPO webpage and the actions it develops: <http://www.yoayudoachicoscondiabetes.org/noticias/cui-d-ar-a-nivel-global-iaipo/>
- IAPO also published information on public policy advocacy actions carried out by CUI.D.AR: <https://www.iaipo.org.uk/news/2018/nov/8/iaipo-member-cuidar-supercharge-their-advocacy-efforts-type-1-diabetes> and <https://www.iaipo.org.uk/iaipo-members-stories-covid-19-2>
- CUI.D.AR was invited to participate in the Survey promoted by the University of Auckland (New Zealand) and IAPO and we helped collect data on the experiences of people with chronic diseases during the COVID-19 pandemic: <https://redcap.nihi.auckland.ac.nz/surveys/?s=L8EJ4AY7M4>

IAPO Governing Board Nomination Form 2020

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 the space below to give details of your participation in regional and international advocacy over the last 2 years (maximum 100 words).

- CUI.D.AR is an entity attached to the UN. We've done joint actions:
<https://www.yoayudoachicoscondiabetes.org/2018/hacemos/> and
https://twitter.com/UNDGC_CS0/status/1276619371696263169/photo/1
- IDF call to action for the 2018 UN High Level Meeting on NCDs
<https://www.flickr.com/photos/idf/albums/72157692467574510>
- World Diabetes Congress (IDF). Delegate for Argentina.
- As a Blue Circle Voice, in global awareness actions:
<https://www.facebook.com/watch/?v=10156374083719447>
- #ActOnNCDs movement of the NCD alliance
- Survey on the impact of COVID-19 on Patients with NCDs in low-income countries.
- I'm part of RediLatam, from 5 Patient organizations from Latin American countries: Mexico, Argentina, Colombia, Ecuador and Brazil.
- I've advised Mexican Organizations for the launch of the Young Leaders Program in diabetes
- I lead, along with 4 other women in Argentina, the #CONSECUENCIAS movement
www.consecuencias.org.ar

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

IAPO Governing Board Nomination Form 2020

Please use the space below 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 100 words).

I've been working tirelessly for almost 20 years to improve the quality of attention, of care, accessibility and quality of life, getting involved in the processes that make up public policies, and I consider that the best tool to make it is through advocacy. But to influence on public policies we need to have different strategies that contemplate the training and empowerment of Organizations, a long-term strategic plan, human and economic resources that make it sustainable and a message with clear objectives about what the needs are but also what are the solutions that we, as Civil Society Organizations, can contribute with.

I share our last action We.CONNECT Diabetes for World Diabetes Day: youtu.be/6iR8fUxtor0

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 150 words).

The role of IAPO, like all non-profit organizations dedicated to health, will be transcendental, but they will also face great difficulties. On the one hand, they must refocus the objectives to include the inescapable reality that the coronavirus imposed, in a new scenario with new rules in an aggiornated agenda that makes sense in this crisis. Undoubtedly in this New Order, where the day after is not clear, IAPO has the opportunity to reaffirm what strengthens it and those battles that it has already fought and is to strengthen its members and transform them into a collaborative Community and more activist than ever to fulfill its objective of focusing attention on the Patient and achieving fairer, inclusive and equitable health for all. It will be essential for IAPO to seek new strategies to form networks, multisectoral alliances and thus achieve a more active participation in the decision-making processes of the countries and regions.

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

(Please keep your answer to no more than 100 words. You can also provide links, e.g. social media or website).

In relation to working together with other IAPO members, I can mention **#Consecuencias** (consequences), emerged as a movement to work on health problems. The main one, access to treatments and medicines for different diseases.

It's made up of 5 women leaders from 6 Patient Associations (most of them are members of IAPO) who come together to give visibility to this problem and precisely to show all the **#Consecuencias** and put the various health issues on the agenda. Our idea is to energize the gears constituted by the State, health providers and Patients. We presented 10 proposals that aim to find solutions with a collaborative dialogue between Patient Associations and governments.

More information at www.consecuencias.org.ar Journalistic note:

<https://www.infobae.com/salud/2020/08/17/las-apasionantes-historias-de-5-mujeres-lideres-que-luchan-por-los-pacientes-de-enfermedades-complejas/>

IAPO Governing Board Nomination Form 2020

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Your nomination

I confirm that the governing body of my organization has approved my nomination as a candidate to IAPO's Governing Board.

I have read the [IAPO's Updated By-Laws](#), [Election Code](#) 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.



Signature

November 14th, 2020

Date

IAPO Governing Board Nomination Form 2020

Please complete this Nomination Form and return to IAPO by email to AGM2020@iapo.org.uk. The deadline for IAPO to receive nominations is **Sunday 14 November 2020 23:59 GMT**. The Nominations Committee will sit and assess all the applications and the assessed information about the 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 nomination 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: Ofra Balaban

Your member organization: CHEN – patient fertility association

Your position at the member organization: Chair

Your email address: amotat_c@netvision.net.il

About you

Please write a short biography or CV below, 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 100 words).

Married, 2 children. MA in Public Policy. Chair of Chen fertility patient association since 1998 – active in changing the laws in Israel for the benefit of the patients. Member and founder of INBAR Israeli rheumatic arthritis foundation. Member of board in FERTILITY EUROPE for the last 3 years. AIA board - African infertility alliance.

Member of the volunteering council in Holon and the women council in my city, Holon. Received twice volunteering award in HOLON and once from the president's wife.

Member in PARE – The European RA (rheumatic arthritis) –active in the EU parliament for patients' rights.

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.

To attend two face-to-face meetings of the Governing Board per year (expenses reimbursed).

IAPO Governing Board Nomination Form 2020

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 are currently suspended.

- 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 two hours (on average) per week to IAPO.
- To ensure that your organization is in good standing and its membership fees are up to date.
- Previous experience on boards or committees at the international, regional or national level.
- Understanding and experience of governance within a non-profit organization.

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, LatAm, Africa, 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?
- Other - Describe below.

Please use the space below to give details of IAPO activities you engaged in since your membership of IAPO and your role in the activity (maximum 150 words).

Biosimilar activities - Globally

FE (Fertility Europe – activities in the EU. PARE Manifesto – I was part of the activity took place in the EU in order to insert the RA diseases in to the list of diseases using the Israel ambassador in Brussels for example in order to provide more MEP's to join us. In WFAM – active in the international survey and other projects in order to increase the awareness to Fertility.

In my country: Israel – active in bringing new laws to the KNESET – the Israeli parliament, regarding patients rights and additional protection for women on fertility treatments and new medicines to the basket of medicines.

IAPO Governing Board Nomination Form 2020

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?
- X Other - Describe below.

Please use the space below to give details of your participation in regional and international advocacy over the last 2 years (maximum 100 words).

In the EU parliament consolation for patients' rights and education regarding sex education.

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)

- X 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)
- X 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
- X Public speaking skills
- X Membership, such as providing membership services and support
- X Organizational development and strategic planning
- X Training, such as running workshops or producing written training/capacity building materials

IAPO Governing Board Nomination Form 2020

Please use the space below 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 100 words).

FE (Fertility Europe – activities in the EU. PARE – part of the activity in the EU in order to insert the RA diseases in to the list of diseases using the Israel ambassador in Brussels for example in order to provide more MEP's to join us. ICSI/WFAM – active in the international survey and other projects in order to increase the awareness to Fertility.
In my country: Israel – active in bringing new laws to the KNESET –Israeli parliament, regarding egg donation laws for women on fertility treatments and new medicines to the basket of medicines especially the Bio-Similar problem.

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 150 words).

A joined activities for rare diseases, recognition to them as important to find medication even it is not economical. Covid-19 makes us work differently and we need to adapt new role of action for the benefit of all of us. Working together will make that happened.

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

(Please keep your answer to no more than 100 words. You can also provide links, e.g. social media or website).

"Doctor Communication a pilot project" – we do it now – The idea came up after I talk with Mr. Kawaldip Sehmi, Chief Executive Officer in Miami meeting. This is a long term mission serve the vision of IAPO. As a collaboration with IAPO in general, with thinking about the importance of communication between all the partners in taking care of a patient, even it is a patient's centered era.

IN Inbar we have cooperation with PARE members and AGORA members.

In FE – we all cooperate in fertility week every November. Some of them are also members in IAPO.

Regarding egg donation we cooperate with the patient group from Argentina. (2007).

<https://www.youtube.com/watch?v=7Djxt3g1Cdk>

<https://www.facebook.com/Chen.lepirion/>

<https://www.youtube.com/watch?v=PX0bhLYW8x0>

IAPO Governing Board Nomination Form 2020

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.

I have read the [IAPO's Updated By-Laws](#), [Election Code](#) 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.

Ofra B.k

עמותת חן לפרייה וחיים
ע.ר. 580320018

November 14, 2020

Signature

Date

עמותת חן לפרייה וחיים
עמותה מס. 580320018 לתרומה לפי סעיף 46
רחוב ויתקין 13, חולון 5851063, טל. 03-5050345
13 Vitkin St. Holon, 5851063 Israel, Tel. 972-3-5050345
E-mail: amotat_c@netvision.net.il, www.amotatchen.org



IAPO Governing Board Nomination Form 2020

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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: Orajitt Bumrungkulswat

Your member organization: Heart to Heart Foundation, Thailand

Your position at the member organization: Committee Member and Assistant Secretary General

Your email address: orajittb@yahoo.com

About you

Please write a short biography or CV below, 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 100 words).

64 years old, lives in Bangkok, Thailand. Bachelor in Economics, Chulalongkorn University, year 1977, Master of Science in Human Settlement Planning and development, Asian Institute of Technology, year 1983.

Other Position: Bangkok Health District Committee Expert, National Health Commission Office. Labour Quality of Life Development Strategy Steering Committee, Health Promotion Fund Office.

Working experience: 42 years, in policy and plan analysis, community plan development, Thailand Social Investment Fund of the World Bank, patient support group/network development, Local Health Promotion Fund development, Patient Centred Healthcare and Patient Engagement in Healthcare System, People Health Security Complaint Centre.

IAPO Governing Board Nomination Form 2020

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.
- ✓ To attend two face-to-face 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 are currently suspended.
- ✓ 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 two hours (on average) per week to IAPO.
- ✓ To ensure that your organization is in good standing and its membership fees are up to date.
- ✓ Previous experience on boards or committees at the international, regional or national level.
- ✓ Understanding and experience of governance within a non-profit organization.

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?
I have attended AGM and Committee meeting in year 2014 and 2019 as an IAPO member.
- ✓ IAPO Strategy Consultation - Which consultation?
IAPO Asia Pacific Steering Committee in year 2012. IAPO SEA Regional Programme Advisory Committee in year 2013, IAPO Strategy 2018-2020 Committee.
- ✓ IAPO Global Patients Congress - Which Congress and what was your role: speaker, moderator, poster exhibitor, other?
IAPO GPC in March 2014 as a speaker.
- ✓ IAPO Regional Meeting (Asia Pacific, LatAm, Africa, etc) - Which have you attended? What was your role in the meeting?
IAPO SEA Regional Meeting in year 2013 as a speaker. IAPO APPC year 2019 as a speaker.
- ✓ IAPO Social Media Campaign - Which and what did you do?
IAPO Member Story under COVID-19 pandemic, a story from Heart to Heart Foundation.
- ✓ Patient Solidarity Day - How have you marked the day?
No activity.
- ✓ WHA and WHO Regional Committees - Which meeting?
Attend 72nd WHA during 20-28 May 2018.
External Policy Consultation - Which consultation?
- ✓ Other - Describe below.

IAPO Governing Board Nomination Form 2020

Please use the space below to give details of IAPO activities you engaged in since your membership of IAPO and your role in the activity (maximum 150 words).

- Participated in IAPO Western Pacific and Southeast Asian Regional Meeting during 12-14 October 2011.
- Involved in IAPO Steering Committee since January 2013.
- Responding to surveys and consultations 6 times.
- Joining IAPO Twinning Program with HKAPO as partner, in 2013.
- Attended IAPO Biosimilar Medicine workshop during 2-3 May 2013 as participant and speaker.
- IAPO representative as a speaker in the FIP International Conference in September 2014.
- Joining the webinar of IAPO 4 time.
- Circulation of IAPO monthly news letter to networks in Thailand.

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?

No.

World Bank and other Bodies consultations - Which ones?

No.

WHO regional advocacy - Where and what issues?

No.

Other - Describe below.

Please use the space below to give details of your participation in regional and international advocacy over the last 2 years (maximum 100 words).

- Attended the Workshop on Strategic Planning on Long Term Care in Hanoi, Vietnam organized by the Asian Development Bank in June 2018 as a speaker.
- Attended the Workshop on Strategic Planning on Long Term Care in Ulaanbaatar, Mongolia organized by the Asian Development Bank in August 2018 as a speaker.
- Attend the 1st-4th Annual South East Asia Breast Cancer Symposium as a speaker since 2017-2019

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

IAPO Governing Board Nomination Form 2020

- 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 the space below 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 100 words).

The particular skills are the patient organization advocacy, capacity building and networking including tool kits and materials for training, patient engagement and patient centred healthcare. The policy proposals and benefit package development for patient-centred healthcare especially under the Universal Health Coverage System. These can be contributed to IAPO by lesson learnt, workshop with members and some collaboration program like twinning program. One example is the Twinning Program between Heart to Heart Foundation and Hong Kong Alliance of Patient's Organizations as partners in year 2013 which was success and fulfil it's objectives.

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 150 words).

IAPO could work parallel with WHO and other international organizations in patient-centered healthcare policy/guidelines and also work with member organizations in order to advocate and circulate the policy/guidelines and also can gather policy proposals from the members including develop indicators, tool kits and materials to be shared among members. Also the strategies and action plans to be developed with member organizations in order for common understanding. Since IAPO have worked closely with WHO so will have crucial role in helping the world recover from the COVID-19 pandemic and build back better in providing knowledge and guidelines about COVID-19 situation and how to prevent from the disease to their members and networks, organizing roundtable discussion and sharing experience about this topic and could provide advices to members for problem solving in some cases.

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

(Please keep your answer to no more than 100 words. You can also provide links, e.g. social media or website).

- Study visit and exchange experiences with Hong Kong Alliance of Patients' Organizations 3 times both in Thailand and Hong Kong.
- Invited IAPO Board Chair Person, Dr.Ratna Devi to be a speaker in the Side Meeting of Prince Mahidol Award Conference 2020 organized by Heart to Heart Foundation and National Health Security Office.

IAPO Governing Board Nomination Form 2020

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Your nomination

I confirm that the governing body of my organization has approved my nomination as a candidate to IAPO's Governing Board.

I have read the [IAPO's Updated By-Laws](#), [Election Code](#) 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.



Orajitt Bumrungkulswat

Signature

31 October 2020

Date