

# IAPO Governing Board Nomination Form 2018



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**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.**

**Your name:** Danjuma K. Adda  
**Your position:** Executive Director  
**Your member organization:** Center for Initiative and Development (CFID) Taraba  
**Your email address:** [cfidtaraba@yahoo.com](mailto:cfidtaraba@yahoo.com); danadda02@yahoo.com

## About you (a Brief Biography)

(Please keep your answer to no more than 100 words)

I am Danjuma K. Adda, married with four kids. I have been living with Hepatitis B, since 2004. My greatest nightmare was when I lost my mother to Hepatitis B in 2007, just few months after my wedding. Since then I dedicated myself to fight Hepatitis.

I established two charity organizations, Chagro-Care Trust (CCT) in 2007, and CFID in 2008 to remove barriers to access to life saving Hepatitis/HIV services. To date in collaboration with MoH and other partners, we have provided access to HIV/hepatitis continuum of services including free HBV vaccination, testing and referrals to over 50,000 people

## 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.
- 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.
- 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.

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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)

- Attended AGM, Congress, Committee meeting (give number and details below)
- Patient Solidarity Day - Have you run an event? What event was it?
- IAPO Regional Meeting (Latam Africa etc)
- WHA 69/70 and WHO Regional Committees
- External Policy Consultation - Which consultation?
- IAPO Social Media Campaign - Which and what did you do?
- IAPO 2018-2020 Strategy Consultation
- IAPO Global Patients Congresses. Speaker, Panel, Poster, other
- Other - Describe. You can also provide LinkedIn and Social Media Links

*Please use this space to give details of IAPO activities you engaged in since your membership of IAPO. Your role in the engagement (maximum 150 words).*

- We joined IAPO in 2016, and since then have played active role in all IAPO activities.
- I applied and was appointed into the IAPO 2018-2020 Strategic Planning Committee. Played an active role in drafting the Strategic Plan with other team members
- African Regional Consultation Meeting, Entebbe: - I actively participated at the African Patient groups consultation meeting held in Entebbe for IAPO African members. I had the privilege of being a speaker at the meeting on a panel, and played an active role in drawing the Entebbe declaration.
- Patient Solidarity Day (PSD):- We celebrated the PSD in Taraba state, Nigeria in a unique style. We mobilized over 10 non-governmental organizations, and CSOs and jointly addressed a media conference on the role of the patient in health care System-Patient Empowerment.
- IAPO Patient empowerment campaign-contributed in writing an article on patient empowerment from the African perspective, published by IAPO in 2017.

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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)

- WHO frameworks and other consultations – Which ones?
- World Bank and Other Bodies consultations - Which ones?
- WHO regional advocacy - Where and what issues?
- Other - Describe. You can also provide LinkedIn and Social Media Links

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

- WHO African Regional Consultation: Brazzaville:- Represented Hepatitis Patient groups at the WHO African regional consultation meeting
- WHO-WHA GHSS 2016-2020; Geneva: Played an active role in the WHO regional consultations on development of the GHSS and participated in the adoption at the World Health Assembly in Geneva, May, 2016
- C20 Global Health Working Group: Member C20 Global Health Working Group advising the G20 on Health matters, actively participated at working groups meetings in Berlin, and the C20 summit held in Hamburg, Germany in June 2017, under German Presidency, where a resolution and communique was presented to the German Chancellor, Angela Merkel.
- Currently involved in C20 2018 Global Health Working Group under the Argentinian presidency.
- Currently a member of the Access to Services Working Group of the International Refugees Congress and playing an active role in drawing up the Action Call and policy recommendations to the UN and other international multilateral institutions.

## 3. What particular skills or expertise could you bring to IAPO's Governing Board? (Please tick all that apply)

- 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
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- Training, such as running workshops or producing written training/capacity building materials

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*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 (maximum 100 words). You may want to include examples of previous experiences or achievements in these areas.*

- **Fund raising:** I have acquired good skills in developing winning proposals, lobbying and resource mobilization, happy to contribute to IAPOs fund raising activities. Played an active role in raising \$1.5million in Taraba Hepatitis Access Program
- **Networking:**-I have skills on building networks, partnerships and collaborative relationships that would assist IAPO greatly, to drive members collaborative work across the regions.
- **Strategic Planning and Organizational Development:** I have skills on Organizational development and strategic planning, assisting organizations strengthen their systems in different capacity domains, ready to support IAPO members across the regions
- **Trainings and Public Speaking:** I am a naturally talented public speaker

# IAPO Governing Board Nomination Form 2018



## 4. What do you see as the opportunities for IAPO's role promoting patient-centred healthcare in the next 5 years?

(Please keep your answer to no more than 100 words)

- Project IAPO as a true global patient focused organization amplifying the patient voice in global advocacy, building on the principle of leave no one behind.
- Strengthen IAPOs role as the global voice for patients from diverse disease conditions working to achieve patient centred health care in attaining the SDG goal and UHC.
- Creates opportunities for empowered patients to actively engage and hold accountable policy makers and other multi-lateral organizations in delivering health care services.
- It would create opportunities for meaningful engagement of patients across the health spectrum-driving the process of change and improved health outcomes

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

You can also provide LinkedIn and Social Media Links

(Please keep your answer to no more than 100 words)

- In Nigeria, my organization being a Hepatitis and Liver focused group, has provided linkage and referrals and support for viral hepatitis continuum of care and treatment for members of an IAPO HIV/AIDS based group.
- We have jointly marked World AIDS Day events as a way of promoting cross cutting challenges of co-infection for our patients.

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 and am committed to the vision and mission of IAPO and agree to uphold IAPO's policies if I am elected to the Governing Board.

Danjuma K. Adda

28/04/2018

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**Your name:** RUBBY CHAWLA

**Your position:** FOUNDER & PRESIDENT

**Your member organization:** INDIAN PATIENTS SOCIETY FOR PRIMARY IMMUNODEFICIENCY-IPSPI

**Your email address:** [rubbychawla@ipspiindia.org](mailto:rubbychawla@ipspiindia.org)

## **About you (a Brief Biography)**

(Please keep your answer to no more than 100 words)

I am 1<sup>st</sup> Merit Post Graduate in Commerce. Served as Professor of Commerce for thirteen years. Ranked 1<sup>st</sup> Merit in PG Diploma in Public Health Services Management, PHFI. Formed PID Society-IPSPI at a National level in 2004. Working as a Chief functionary since then. Have contributed an article in Pharmaceuticals Policy And Law, (Volume 10, 2008) by Prof. J.L.Valverde & D.Watters, on PID. Board Member of Team India for Orphan Diseases/Drugs TIOODD – Pharmexcil / IPS (Indian Pharmacological Society). Organized various National & International CMEs and Workshops on PID and was the speaker in various Regional, National and International Conferences and panellist in rare diseases in India and Singapore. Represented India in Conferences & Biennial Meetings of IPOPI, ESID and INGID and IAPO GPC Congress 2016.

## **Requirements and commitments of Governing Board members**

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✓ Understanding and experience of governance within a non-profit organization.

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- IAPO 2018-2020 Strategy Consultation
- ✓ IAPO Global Patients Congresses. Speaker, Panel, Poster, other
- Other - Describe. You can also provide LinkedIn and Social Media Links

*Please use this space to give details of IAPO activities you engaged in since your membership of IAPO. Your role in the engagement (maximum 150 words).*

I participated in the first IAPO South-East Asia meeting at New Delhi and later contributed a case study for IAPO South-East Asia Regional Programme report 2013 . I was selected for representing South East Asia by IAPO in SEARO WHO meeting at DILI, TIMOR-LESTE. Contributed as a stakeholder to the IFPMA-IAPO Health Policy Partnership by Interview on Biotherapeutics & Biosimilars. Participated in various IAPO,WHO Surveys. Participated as a speaker in IAPO GPC 2016.Participation in Meetings of formation of IAPG-Indian Alliance of Patients Group as Core Group Member on 24<sup>th</sup> April,2015 in Taj Mansingh, New Delhi and meeting at Hotel Taj, New Delhi alongwith Linda M.Distlerath, Deputy Vice President, International Alliance Development, Pharma, Scott A. LaGanga, Senior Vice President, Public affairs & Advocacy, Pharma, Kevin L. Walker, Executive Director, PFCD on 8<sup>th</sup> August,2015 and launch of IAPG in Mumbai.

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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)

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- WHO regional advocacy - Where and what issues?
- Other - Describe. You can also provide LinkedIn and Social Media Links

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

Participated in International Conferences & Biennial Meetings of IPOPI, ESID, INGID in Barcelona, Spain in 2016, First South-east Asia Meeting in HongKong in April 2016 and Global Congress of IAPO 2016 in London; as speaker & moderator in BioPharma Asia Convention 2016 at Singapore. National, regional and state advocacy to Centre and State Government of India, Medical Institutions and Doctors through CMEs, General Public through Silent march, press and media coverage and distribution of Posters, pamphlets and leaflets. Advocacy by participation in National Consultative High Delegates Closed Group Meeting for the formulation & implementation of policy on treatment of rare diseases at New Delhi in April 2017.

## 3. What particular skills or expertise could you bring to IAPO's Governing Board? (Please tick all that apply)

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Meetings with DGHS, HFW Ministers, HFW Secretary, Center and State Government of India and more than a decade long struggle for the patients of PID to get free treatment had positive outcome. Achievement: we have the National Policy for treatment of PID (under rare diseases) and State Government has started free PID treatment in some States of India. The continuous advocacy with the medical fraternity & Government gave an insight into healthcare system. I have worked for the advocacy at large and can help IAPO to strengthen its goals on Patient-centred Healthcare, Capacity building to strengthen patients voice and fulfil its mission on Universal Health coverage and Healthcare for all.

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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?

(Please keep your answer to no more than 100 words)

IAPO has an important & crucial role to play in the promotion of patient-centred healthcare in the developing nations. IAPO can develop tools for the guidance of policy-makers where Allocation of Health budget is meagre. IAPO is the only organization to address & educate patients globally to have strong voice in their country to have access to care and treatment. In developing nations though they speak of holistic approach to healthcare, but practically healthcare at the primary, secondary or tertiary levels is pathetic. Promotion of patient-centred healthcare at these levels is urgently required. Patients should be educated about their basic human rights to have universal access to safe & quality health-care with dignity.

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

You can also provide LinkedIn and Social Media Links

(Please keep your answer to no more than 100 words)

Contributed an article in the Case-study for South-East Asia Regional Programme report 2013 and participated in surveys conducted by IAPO. I was one of the Panelist in Panel1-The role of the patient advocate and best practices in advancing patient-centered principles in healthcare reform & gave presentation on the benefits of international networks/leveraging international advocacy networks in the National Patient Advocacy Network-Founding Meeting by IAPO at New Delhi on 12<sup>th</sup> November ,2014. I was selected to represent South East Asia by IAPO in SEARO WHO meeting at DILI, TIMOR-LESTE from 7-9 Sep.,2015.I was the speaker on Day1 & facilitator on Day2 at IAPO Global Patients Congress 2016 in London. Contributed as a stakeholder to the IFPMA-IAPO Health Policy Partnership by Interview on Biotherapeutics & Biosimilars.

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**Your name:** ROBINAH KAITIRITIMBA

**Your position:** Executive Director

**Your member organization:** UGANDA NATIONAL HEALTH USERS/CONSUMERS' ORGANISATION

**Your email address:** rkitungi@yahoo.com, rkitungi@unhco.or.ug

## **About you (a Brief Biography)**

(Please keep your answer to no more than 100 words)

Robinah is Executive Director Uganda National Health Consumers' Organization, World Health Organisation (WHO) Patient Champion, holds a Master's degree in Management, Bachelors of Arts, trained in Health and Human Rights, policy advocacy and leads a coalition of patients' organisations, As health consumers representative, She is a member of Institutional Review Board (IRB) of Makerere University School of Public Health, Board member of Uganda National Council of Science and Technology (UNCST), Board member of New Vision newspaper, Board member for Uganda Health care Federation, Board member of Reproductive Health Uganda. She represents civil society at the national Health Policy Advisory Committee, has contributed to the development of various health policies including the VHT strategy, National Health Policy. She is a member of various boards of organizations and skilled in research, Community Participation and Social Accountability.

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- IAPO Regional Meeting (Latam Africa etc) Took part in the
- WHA 69/70 and WHO Regional Committees ✓
- External Policy Consultation - Which consultation?
- IAPO Social Media Campaign - Which and what did you do? ✓
- IAPO 2018-2020 Strategy Consultation ✓
- IAPO Global Patients Congresses. Speaker, Panel, Poster, other ✓
- Other - Describe. You can also provide LinkedIn and Social Media Links

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As the WHO Patients for Patient Safety representative, on the 3<sup>rd</sup> Global Ministerial Summit on Patient Safety in Tokyo- Japan April 13-14, 2018 I read the IAPO statement, increased IAPO membership in Uganda, reported and participated for Afro region members, made presentations to the FIGO conference in South Africa in 2009, on May 3<sup>rd</sup> 2011 was a Speaker, Medical devices forum Bangkok, participated in the APPS strategy Group- 2011-2013, IAPO African Regional Network plan 2011-2012. My organisation led the drafting of the position paper for the African Union on AMA in the 2017 in the African IAPO conference held at Entebbe- Uganda and we are leading the enactment process of the patient rights Bill in Uganda.

I conducted a survey on mother and baby tool in Uganda, contributed to development of the 2005 London Declaration, Roadmap for patient engagement and the follow up Afro-Declaration. Member of expert group on WHO patient and Family engagement framework, guidelines for prevention of surgical site infections and the Advisory committee on partnerships with patients.

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- WHO regional advocacy - Where and what issues?
- Other - Describe. You can also provide LinkedIn and Social Media Links

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

Read IAPO statement at the 3rd Global Ministerial Summit on Patient Safety Tokyo, Japan that took place in April 13-14, 2018. Awarded on the 8<sup>th</sup> of March 2018 by the WHO NCDs ambassador the for enforcing tobacco advertising Promotion and sponsorship the MPOWER awards at the World tobacco or Health Conference at Cape town South Africa, participated in the development of the WHO global guidelines for prevention of onsite surgery infections, participated in the African Collaborative for Health Financing Solutions' Regional Workshop to be held in Accra, Ghana in February 2018.

<https://www.facebook.com/unhco/videos/vb.137387592962009/1835440809823337/?type=2&theater>

## 3. What particular skills or expertise could you bring to IAPO's Governing Board? (Please tick all that apply)

- 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) ✓
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1. **Patient rights Advocacy:** on the 8<sup>th</sup> of March 2018, I am a received the Bloomberg Philanthropies MPOWER Awards for leading CSOs in the enactment processes and enforcement of the tobacco control Act of Uganda;
2. **Patient rights Bill:** initiated and lead processes to fast track a patient empowering legislation in Uganda;
3. **Public speaking skills;** Read IAPO statement at the 3rd Global Ministerial Summit on Patient Safety Tokyo, Japan that took place in April 13-14, 2018.
4. **Lobbying government;** Represent CSOs on Ministry of Health Highest policy making organ, Afro Regional WHO Patients for Patient Safety Representative, led CSOs in the 1999 patient charter of Uganda adoption process by the Ministry of Health of Uganda.

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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?

(Please keep your answer to no more than 100 words)

Advocate for domesticating Universal Health Coverage by partners, Fast track enabling laws to entrench constitutional inclusion of the right to health, Deepen patient- health worker centred relationship for smooth feedback, Make routine national, regional and continental IAPO activities to keep the patient safety movement alive and Participate in the African Union medicine regulations processes.

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

You can also provide LinkedIn and Social Media Links

(Please keep your answer to no more than 100 words)

Uganda National Health Consumers Organisation supports IAPO position AMA arrived at in Entebbe of July 4<sup>th</sup> – 5<sup>th</sup> 2017 and has endorsed it for processing by IAPO (<https://twitter.com/search?q=%23IAPOAfrica17>); tweets, retweets, shares information shared by IAPO to benefit members outside IAPO for purposes of enticing them to Join the prestigious membership of IAPO, UNHCO finds it her noble duty to market IAPO positions wherever platforms avail themselves.

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\_\_\_\_\_  
Signature

26<sup>th</sup> April 2018

\_\_\_\_\_  
Date

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**Your name: ELLOS ELLARD LODZENI**

**Your position: PATRON AND FOUNDER TRUSTEE**

**Your member organization: PATIENT AND COMMUNITY WELFARE FOUNDATION OF MALAWI (PAWEM)**

**Your email address: lodzene@yahoo.co.uk**

## **About you (a Brief Biography)**

(Please keep your answer to no more than 100 words)

**ELLOS IS A HEALTH RIGHTS, SOCIAL JUSTICE AND GOVERNANCE ADVOCATE AS WELL AS A PATIENT FOR PATIENT SAFETY CHAMPION WITH AN ENORMOUS PASSION ON HEALTH MATTERS. HE FOUNDED THE ONLY CROSS DISEASE PATIENT MOVEMENT IN MALAWI IN 2008 WHICH ARTICULATES AND AMPLIFIES THE PATIENT VOICE AND DRIVES THE CRUSADE FOR PATIENT CENTRED HEALTH CARE IN MALAWI. HE HOLDS A MASTER OF ARTS DEVELOPMENT DEGREE FROM THE UNIVERSITY OF EAST ANGLIA, UK. HE HAS OVER 30 YEARS PUBLIC SECTOR EXPERIENCE. CURRENTLY AS A FULL TIME EXECUTIVE SECRETARY IN THE OFFICE OF THE OMBUDSMAN HE CONTINUES TO ADVANCE THE PROTECTION AND PROMOTION OF RESPECT TO HUMAN AND HUMAN RIGHTS RIGHTS. HE IS AN EXCELLENT ACHIEVER AND COORDINATES VERY WELL WITH HEALTH INSTITUTIONS- BE IT PUBLIC AND CIVIL SOCIETY. HE HAS BROKEN THE SILENCE ON HEPATITIS IN MALAWI. AND GOVERNMENT-THE MALAWI MINISTRY OF HEALTH IS NOW RECOGNISING AND PROGRAMMING ON HEPATITIS**

## **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.

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.

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.



# IAPO Governing Board Nomination Form 2018



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

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

**Please answer the questions below.**

**1. What IAPO activities did you engage in since your membership of IAPO?** (Please tick all that apply)

- Attended AGM, Congress, Committee meeting (give number and details below)
- Patient Solidarity Day - Have you run an event? What event was it?
- IAPO Regional Meeting (Latam Africa etc)
- WHA 69/70 and WHO Regional Committees
- External Policy Consultation - Which consultation?
- IAPO Social Media Campaign - Which and what did you do?
- IAPO 2018-2020 Strategy Consultation
  - IAPO Global Patients Congresses. Speaker, Panel, Poster, other
  - Other - Describe. You can also provide LinkedIn and Social Media Links

*Please use this space to give details of IAPO activities you engaged in since your membership of IAPO. Your role in the engagement (maximum 150 words).*

*I ATTENDED THE IAPO ANNUAL CONGRESS IN 2012 AND ALSO PARTICIPATED AS A SPEAKER. IN ADDITION I WAS A MEMBER IN THE ORGANIZING COMMITTEE FOR THE CONGRESS AND MADE MY CONTRIBUTIONS THROUGH SKYPE.*

*I ALSO ATTENDED THE IAPO AFRICA REGIONAL MEETING IN KAMPALA AND THE WHO FIRST PATIENT FOR PATIENT SAFETY MEETING WHICH WAS HELD IN JOHANNESBURG SOUTH AFRICA.*

*I SPEARERHEADED THE FORMATION OF NATIONAL ALLIANCE OF PATIENT ORGANIZATIONS IN MALAWI (NAPOM) AN UMBRELLA ORGANIZATION FOR PATIENT ORGANIZATIONS*

*LATELY I HAVE PIONERRED THE ESTABLISHMENT OF PAWEM DISTRICT CHAPTERS IN ORDER TO ENURE THAT THE PATIENT VOICE IS ARTICULATED IN THE ENTIRE COUNTRIES THROUGH VOLUNTARY MEMBERS.*

*PAWM OPERATES ON VOLUNTARY BASIS WE DO NOT HAVE REGULAR DONOR FUNDING HENCE I USE MY PERSONAL RESOURCES IN MOST OF THE ADVOCACY WORK INCLUDING TRAVEL AND COMMUNICATIONS*

*IN 2017 PAWEM ORGANIZAD COMMEMORATION ACTIVITIES ON PATIENT SOLIDARITY DAY WITH FUNDING FROM IAPO. WE ALSO ONCE RECEIVED A GRANT FROM IAPO WHERE WE*

# IAPO Governing Board Nomination Form 2018



## 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)

- WHO frameworks and other consultations – Which ones?
- World Bank and Other Bodies consultations - Which ones?
  - WHO regional advocacy - Where and what issues?
  - Other - Describe. You can also provide LinkedIn and Social Media Links

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

*I AM A MEMBER OF THE WORLD HEPATITIS ALLIANCE- A BODY WHICH ADVOCATES FOR RAISING AWARENESS, TREATMENT AND DIAGNOSIS OF HEPATITIS. I PARTICIPATE IN THEIR ANNUAL MEETINGS-SCOTLAND AND BRAZIL SUMMITS AND VARIOUS CONSULTATIONS ELECTRONICALLY. IN AFRICA I PARTICIPATE ON HEPATITIS ADVOCACY THROUGH THE AFRICAN LIVER PATIENTS ALLIANCE ASSOCIATION (ALPA)- CAIRO, EGYPT.*

## 3. What particular skills or expertise could you bring to IAPO's Governing Board? (Please tick all that apply)

- 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 (maximum 100 words). You may want to include examples of previous experiences or achievements in these areas. I*

*HAVE EXTENSIVE ADVOCACY AND NETWORKING SKILLS. IAPO IS NOT WELL PUBLISHED IN AFRICA ESPECIALLY THE SOUTHERN AFRICA. I WOULD WANT TO BRING MANY MEMBERS FROM THIS REGION. I WOULD ALSO ADVOCATE MORE IAPO VOICE IN SADDCC THROUGH OUR MINISTRY OF HEALTH AND OTHER CIVIL SOCIETY ORGANIZATIONS AND GOVERNMENT AGENCIES. THE WHO AFRICA REGIONAL OFFICE ALSO NEEDS TO RECOGNIZE IAPO MORE STRONGLY. ONLY THROUGH THIS CAN SOUTHERN AFRICAN COUNTRIES ENTRENCH MORE STRONGLY PATIENT CENTRED HEALTH SERVICE DELIVERY. IAPO NEEDS TO COLLABORATE WITH GOVERNMENT ACCOUNTABILITY INSTITUTIONS MORE CLOSELY*

# IAPO Governing Board Nomination Form 2018



*SUCH AS OFFICES OF THE OMBUDSMAN AND HUMAN RIGHTS INSTITUTIONS, PARLIAMENTARY COMMITTEES ON HEALTH SO THAT PATIENT CENTRED HEALTH CARE IS DEEPLY ENTRENCHED. THE HOSPITAL OR HEALTH FACILITY OMBUDSMAN CONCEPT NEEDS TO BE ADOPTED IN ALL PUBLIC HEALTH FACILITIES SO THAT PATIENTS ARE GIVEN A VOICE AND IN THE PROCESS ENTRENCH PATIENT CENTERD HEALTH CARE.*

*I WOULD ALSO ARTICULATE THE PRINCIPLE OF WORKING MORE CLOSELY WITH GOVERNMENT HEALTH MINISTRIES AS WELL AS PATIENT ORGANIZATIONS*

# IAPO Governing Board Nomination Form 2018



#### **4. What do you see as the opportunities for IAPO's role promoting patient-centred healthcare in the next 5 years?**

(Please keep your answer to no more than 100 words)

TO BE A CENTRE OF EXCELLENCE AND RESPOSITORY FOR PROVISION OF BEST PRACTICES IN PATIENT CENTRED HEALTH CARE, TO ARTICULATE AND ASSIST IN THE MOBILIZATION AND PROVISION OF INFORMATION ON POSSIBLE RESOURCES FOR PATIENT ORGANIZATIONS IN THE RESOURCE LIMITED COUNTRIES, TO ASSIST PATIENT ORGANIZATIONS WITH TECHNIQUES ON HOW TO CLOSELY NETWORK IN THEIR REGIONS, PRACTICAL CAPACITY BUILDING OF PATIENT ORGANIZATIONS IN RESOURCE MOBILIZATION AND ADVOCACY AND TO BRING A STRONG PATIENT VOICE IN WHO REGIONAL OFFICES-ESPECIALLY AFRO

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

You can also provide LinkedIn and Social Media Links

(Please keep your answer to no more than 100 words)

-WORKING HAND IN HAND AND MORE CLOSELY WITH THE WORLD HEPATITIS ALLIANCE  
-COLLABORATING WITH THE MALAWI WHO OFFICE  
-STRONGLY ADVOCATING FOR HEPATITIS PROGRAMMING THROUGH THE AFRICAN LIVER PATIENT ASSOCIATIONS MOST OF THE MEMBERS IN IT ARE ALSO IAPO MEMBERS  
-LIASING WITH THE UGANDA ALLIANCE OF PATIENT ORGANIZATIONS SO THAT WE SHOULD ESTABLISH A STAFF EXCHANGE PROGRAMME BETWEEN 2018 AND 2019 WITH POSSIBLE FINANCIAL SUPPORT FROM NORWAY EXCHANGE

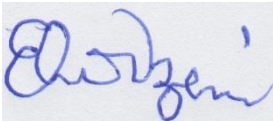
Please note, appointment as a Governing Board member for IAPO requires commitment to IAPO's mission and vision, the acceptance of UK charity and company regulations and good practice for boards of trustees of a charity and an understanding that serving as a Board member is not for personal gain nor for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

#### **Your nomination**

# IAPO Governing Board Nomination Form 2018



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

\_30/04/2018

*D*

# IAPO Governing Board Nomination Form 2018



Please complete this Nomination Form and return to IAPO by post or email to [info@iapo.org.uk](mailto:info@iapo.org.uk). The deadline for IAPO to receive nominations is **Monday 30 April 2018**. 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 nominations booklet.**

**Your name: KAREN IDA VILLANUEVA**

**Your position: VICE-PRESIDENT**

**Your member organization: PGILIPPINE ALLIANCE OF PATIENT ORGANIZATIONS**

**Your email address: karenidavillanueva@gmail.com**

## **About you (a Brief Biography)**

(Please keep your answer to no more than 100 words)

Karen has devoted her 20-yr experience in the pharmaceutical industry to advancing patient rights through her support of the Philippine Alliance of Patient Organizations (PAPO) where she currently serves as Vice President. After corporate, she served as Member of the Board of Philippine Health Insurance Corporation, the country's national insurance agency. She was also consultant at the Department of Health for Health Promotions and Communications.

Her most recent corporate post was as External Affairs Director of MSD handling communications, policy, commercial innovation and market access. She was previously Corporate Affairs Director of Pfizer Philippines and Communications Manager of Zuellich Pharma.

## **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.

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.

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.

# IAPO Governing Board Nomination Form 2018



Understanding and experience of governance within a non-profit organization.

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

## Please answer the questions below.

**1. What IAPO activities did you engage in since your membership of IAPO?** (Please tick all that apply)

Attended AGM, Congress, Committee meeting (give number and details below) 2016 International Patients Congress

Patient Solidarity Day - Have you run an event? What event was it? PAPO observed Patient Solidarity Day last Dec. 6, 2017 with the IAPO theme "Globally Empowered Patients: Power through Knowledge"

IAPO Regional Meeting (Latam Africa etc)

WHA 69/70 and WHO Regional Committees: 69<sup>th</sup> WHA, Geneva

External Policy Consultation - Which consultation? WHO WPRO TAG on UHC, WHO WPRO Hospital Planning & Management, DOH Phils on Anti-Hospital Detention Act, UHC Act, Drug Price Regulatory Board Bill, Patient Safety & Safe Medicines, Framework for Ethical Collaboration between Patient Groups and the Pharmaceutical Industry

IAPO Social Media Campaign - Which and what did you do? Thunderclap for Patient Solidarity Day

IAPO 2018-2020 Strategy Consultation

IAPO Global Patients Congresses. Speaker, Panel, Poster, other: Participated in the IAPO AVP

Other - Describe. You can also provide LinkedIn and Social Media Links

*Please use this space to give details of IAPO activities you engaged in since your membership of IAPO. Your role in the engagement (maximum 150 words)*

In May 2015, I met with IAPO CEO Kewaldip Sehmi to reiterate PAPO's commitment to IAPO. In October 2015, I represented IAPO in the WPRO Meeting in Guam. I also attended the 7<sup>th</sup> Global Patients Congress in April 2016 where I participated in a video about IAPO. I met up with Kawaldip Sehmi in the World Health Assembly in Geneva while I was part of the Philippine delegation. In October, I also represented IAPO as an observer during the first UHC Technical Advisory Group. Last 2017, I again represented IAPO in the 2<sup>nd</sup> UHC TAG Meeting. We align with IAPO in the observance of Patient Solidarity Day and its push for patient-centered health care. I regularly communicate with IAPO consulting them on issues on patient safety, HTA, HC among others, to ensure PAPO is aligned in terms of our policy advocacy.

# IAPO Governing Board Nomination Form 2018



## 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)

- WHO frameworks and other consultations – Which ones?
- World Bank and Other Bodies consultations - Which ones? Policy consultation on Provider Payment Mechanism – EU & Philhealth
- WHO regional advocacy - Where and what issues? Universal Health Care & Hospital Planning & Management
- Other - Describe. You can also provide LinkedIn and Social Media Links

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

I have been active in the advocacy on Patient-centered healthcare and Universal Health care. I have also participated in the NCD Alliance and Rare Cancer meetings as means of calling attention to the need for a concerted effort to address NCDs.

## 3. What particular skills or expertise could you bring to IAPO's Governing Board? (Please tick all that apply)

- 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 2018



*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 (maximum 100 words). You may want to include examples of previous experiences or achievements in these areas.*

My experience in communications and policy work is something I can contribute. I am also skilled in developing partnerships with the pharmaceutical industry as well as with civil society and government. I am skilled in policy advocacy and have contributed in the goal for Universal Health Care. I also sit in various Technical Working Groups, participate in public hearings and speak on patient participation in policy-making. As a communications professional, I can contribute to developing strategy, messaging and reputation management. Finally, I have a business background so I understand the importance of strategic planning and financial management.

# IAPO Governing Board Nomination Form 2018



#### 4. What do you see as the opportunities for IAPO's role promoting patient-centred healthcare in the next 5 years?

(Please keep your answer to no more than 100 words)

IAPO will play a very significant role in ensuring patients are at the center of Universal Health Care by providing the vision, the tools and the global advocacy for the patient groups in the different countries. PAPO is very thankful to IAPO for being a resource and providing guidance on the developments that will impact our own efforts in the country.

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

You can also provide LinkedIn and Social Media Links

(Please keep your answer to no more than 100 words)

There is still a huge opportunity for PAPO to liaise with other IAPO members.

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 and am committed to the vision and mission of IAPO and agree to uphold IAPO's policies if I am elected to the Governing Board.

Karen Ida Villanueva

28 April 2018

\_\_\_\_\_  
*Signature*

\_\_\_\_\_  
*Date*

# IAPO Governing Board Nomination Form 2018



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**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.**

**Your name:** Ya Hsin Wang  
**Your position:** General secretary  
**Your member organization:** Psoriasis Association Taiwan  
**Your email address:** psotaiwan@gmail.com

## About you (a Brief Biography)

(Please keep your answer to no more than 100 words)

My name is Ya Hsin Wang from Taiwan. I graduated from Taipei Medical University in nutrition and health science. I was also a dietician before. I am secretary-general of Psoriasis Association Taiwan now. 22 years ago, I suffered from psoriasis and it brought me much pain. However, my patient journey also let me have deep sympathy with patients' suffering. Since 2017, I was selected as important committee member in national health insurance committee and representative of medical service payment in PBRS, ministry of health and welfare in government. I sincerely hope patient-centred can come true through our efforts.

## 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.
- ✓ 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.
- ✓ 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.

# IAPO Governing Board Nomination Form 2018



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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)

√ Attended AGM, Congress, Committee meeting (give number and details below)

√ Patient Solidarity Day - Have you run an event? What event was it?

IAPO Regional Meeting (Latam Africa etc)

WHA 69/70 and WHO Regional Committees

External Policy Consultation - Which consultation?

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

IAPO 2018-2020 Strategy Consultation

IAPO Global Patients Congresses. Speaker, Panel, Poster, other

√ Other - Describe. You can also provide LinkedIn and Social Media Links

*Please use this space to give details of IAPO activities you engaged in since your membership of IAPO. Your role in the engagement (maximum 150 words).*

2016.4 Attending IAPO 7th Global Patients Congress

2017.8 Assisting for translation of poster content “the future we want” from English into Chinese.

2017.9 Participate the PSD activities via social media (FB) and let more worldwide patients know about the importance of patient-centred in healthcare system. At the same time, I also attend the future trend(the international congress in Taiwan ,participants including patients group leaders, doctor, scholars and government officers)to communicate, exchange information , and let them understand more about patients’ unmet needs.

2017.10 Warmly receive speakers visiting Taiwan from IAPO.

2017.12 Post article on IAPO website relating about PSD

(<https://www.iapo.org.uk/news/2017/dec/15/psoriasis-association-taiwan-marks-psd-future-trends-forum-2017>)

### 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)

WHO frameworks and other consultations – Which ones?

World Bank and Other Bodies consultations - Which ones?

# IAPO Governing Board Nomination Form 2018



WHO regional advocacy - Where and what issues?

√ Other - Describe. You can also provide LinkedIn and Social Media Links

Since 2011, World Psoriasis Day activities series were held in Taiwan. There are many different patterns of activities ever held, such as press conference, exercise walking, Concert, and Forums. Through the media, we spread correct cognition of psoriasis to the public and government, and also showing patients' unmet needs for many officers in government to build an appropriate health care system for patients.

As a national health insurance committee member, I voice the patients' standpoints for other committee members, although there is still some difficulties to overcome, I think it's very worth and important to do it in my life.

**3. What particular skills or expertise could you bring to IAPO's Governing Board?** (Please tick all that apply)

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 (maximum 100 words). You may want to include examples of previous experiences or achievements in these areas.*

Besides the profession of dietician, nutrition, and committee member of the national healthcare system, I also invited famous musicians to create the first pop song and MV about patients' voice—"Love as Sunshine", which let the press understand the suffering of diseases. I went to TV programmes to share my experiences and encourage patients to face the challenge. In addition, I established a website for our NPO organization and apply the social media, such as FB, Line, to connect more patients and found unmet needs. These skills including my experiences of holding activities for advocacy can contribute a lot.

# IAPO Governing Board Nomination Form 2018



## 4. What do you see as the opportunities for IAPO's role promoting patient-centred healthcare in the next 5 years?

(Please keep your answer to no more than 100 words)

The main purpose of the health care system established is caring patients well. Due to aging and increasing chronic diseases, I think more and more countries, especially in Asia, will face big challenges. For examples, how to distribute the limited budget appropriately, how to make the medical system more effectively, and how to reduce the medical waste etc. In the next 5 years, to solve these existing huge problems, applying patient-centred core concepts and HTA into the medical environment is the necessary trend in the future. Therefore, IAPO can promote patients to have stronger standpoint to involve health decision-making system.

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

You can also provide LinkedIn and Social Media Links

(Please keep your answer to no more than 100 words)

PAT is also one of the members of International Federation of Psoriasis Associations. We have involved and collaborated with IFPA, especially many activities in Asia. Every year, there is a common theme for World Psoriasis Day globally and PAT run different events to respond to different themes, too.

The below linkage is World psoriasis Day video last year:

<https://www.facebook.com/internationalfederationofpsoriasisassociations/videos/vb.180731365279475/1655164047836192/?type=2&theater>

I am also the Executive Director of Taiwan Alliance Patients' Organization. In addition, PAT cooperate other IAPO members in Taiwan and integrates the cross-disease species perspectives to reflect the patients' voice to the decision-making key person, legislators, and government officers.

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 and 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*

\_\_\_\_\_  
*Date*