

## IAPO 2020 Highlights

### IAPO strategy in 2020

In 2020, the second year of our 2019-2021 Strategic Plan, our vision remained to see patient-centred universal health coverage (PC-UHC) established in all countries, and our objective were to ensure that there is a sufficient availability of patient-centric, safe and quality promotive, preventive, curative, rehabilitative and palliative healthcare services in each WHO Member State, along with essential and innovative medicines and health devices, which are accessible, acceptable and affordable, and delivered without the patients suffering financial hardship or discrimination.

Our 2020 strategy was to:

1. Empower patient communities globally to advocate effectively for patient-centred universal health coverage for all.
2. Drive research processes and the development of evidence base for patient-centred universal health coverage.
3. Shape law, policy and practice in patient-centred universal health coverage at global, regional and national levels.

### Shape law, policy and practice in patient centred-universal health coverage at global, regional and national levels

#### IAPO's anniversary – 21 years of shaping our healthcare ecosystem

IAPO was formed in 1999 as a response to developments in healthcare that were increasingly marginalising patients by restricting participation and engagement. IAPO wanted to put the patient back at the centre of all healthcare decision and policy-making. While we have surmounted most of the traditional barriers in healthcare during the past 21 years, the modern healthcare landscape has changed dramatically over the last decade. Rapid globalisation, digitised and innovation within healthcare has created new challenges and barriers for us.

While 2020 was to celebrate the year in which IAPO came of age, the COVID-19 pandemic shook every patient organization and health system around the world. The pandemic disrupted all our plans to welcome our members to an amazing anniversary dinner at the National Museum of Scotland in their great exhibition hall, where great scientists like Charles Darwin had developed their scientific theories, and which housed Dolly the sheep (the first cloned animal). We had to curtail all celebrations acknowledging the great global mortality, morbidity and suffering.

This year, very early during the pandemic, we sadly lost our Board Member Carol Ossai to COVID-19 (RIP) who was a strong advocate for the improvement of care and treatment for people living with sickle cell diseases.

To mark our 21<sup>st</sup> anniversary, IAPO and its Board and staff have developed a short video telling IAPO's story: <https://bit.ly/37Akolj>

## IAPO collaboration with the World Health Organization

### *73<sup>rd</sup> World Health Assembly*

IAPO participated in perhaps the most important World Health Assembly in the entire 72 years of the World Health Organization (WHO). WHA 73 was a single-issue assembly where all 194 Member States came together in national unity and global solidarity to address the COVID-19 pandemic. More than this, over 200 non-State Actors in official relationship with the WHO took particular care to submit statements as part of their interventions.

IAPO joined WHA 73 through the non-State Actor Office and submitted a comprehensive statement to Agenda Item 73.1.3 COVID-19 Response noting we were appalled to see how lockdowns without plans and lack of patient engagement resulted in great lapses of patient safety, breaches of human rights (police action) and loss of trust in health systems. Patient safety and health professional safety was compromised by lack of healthcare availability, access, acceptance and quality. We urged all WHO Member States to adopt a human rights-based approach to their public health measures. Full statement can read here: <https://bit.ly/3p9mMp6>

### *WHO Regional Committees*

We participated virtually in the WHO Regional Committees:

- Regional Committee for the Western Pacific
- Regional Committee for Europe
- Regional Committee for Africa
- Regional Committee for South-East Asia
- Regional Committee for the Americas
- Regional Committee for the Eastern Mediterranean Region

## AMR Patient Alliance

IAPO along with patient organizations from different regions and countries has developed a Global Patient Consensus Statement and a Call to Action, that aims to convene civil society groups representing patients, carers and advocates in a global AMR Patient Alliance, which was partly launched in December. The AMR Patient Alliance will be a place where patients can exchange views, be educated, and acquire knowledge and resources that we need to raise awareness about the importance of sustaining the efficacy of antibiotics - for as long as possible, for as many patients as possible. Learn more about the Alliance here:

<https://bit.ly/3nE4GLF>

## Fight the Fakes Alliance

IAPO is a founding member of the new Fight the Fakes (FTF) Alliance, a new multi-stakeholder non-profit association registered in Geneva (Switzerland), set up to fight against falsified medicines. Seven years since its first activities as a grass root advocacy campaign, the new formal governance structure will allow the FTF Alliance to take the fight against substandard and falsified medicines to the next level. With over 15 members representing health care professionals, manufacturers, wholesalers, researchers and patients, the Alliance is uniquely positioned to scale up action to prevent falsified medicines from endangering people's health and well-being. More information on this: <https://bit.ly/2Jc0a8c>

## 10th Asia Regulatory Conference

Ratna Devi, IAPO Chair, participated in the panel discussion 'Patients Perspectives on Regulatory Reliance and Why Patient Engagement is Important'. In order to secure early access to innovative quality and safe medications, it is important that market authorization process is streamlined across Asia. Regulatory Reliance is a process through which national medicines regulatory authorities cooperate and streamline market authorization processes.

## Campaign to ratify the African Medicines Agency Treaty

Two years after we issued our Entebbe Statement on the African Medicines Agency (AMA) in 2017, we had hoped we would have AMA set up by 2019. This has not happened. The IAPO campaign explores the benefits of establishing the African Medicines Agency and what is preventing the signing and ratification of the Treaty to establish the AMA. In partnership with African organizations, WHO and the International Federation of Pharmaceutical and Manufacturers Association, IAPO began the campaign to address this at the Geneva Health Forum. You can watch the session via this link: <https://bit.ly/2J8hLxI>

AMA's main objectives are improving access to safe and affordable medicines, boosting local manufacturing, and taking concerted action to tackle substandard and falsified medicines. It will also help to support the growth of local pharmaceutical companies and drug manufacturing, one of the key aims of the Pharmaceutical Manufacturing Plan for Africa and the Africa Continental Free Trade Area. If it was not a priority before, then with the COVID-19 pandemic, there can be no other priority but AMA to ensure safe vaccines, biotherapeutics and repurposed medicines from WHO.

## Empower patient communities globally to advocate effectively for patient centred-universal health coverage for all

### 9th Global Patients Congress

The 9th Global Patients Congress (GPC 2020) held on 16-17 September 2020 was one of the most critical congresses in our 21-year history. Holding a patients congress in the middle of a pandemic was very important to raise the patient voice in all the public health decision-making taking place globally. It was also key that we showed global solidarity with all the stakeholders engaged in controlling and hopefully eliminating COVID-19. The Congress was unique as it invited top scientists, policy makers, and Non-State Actors to speak to our members.

The Congress was also important because it was marking the 2<sup>nd</sup> World Patient Safety Day on 17 September when patient harm and health professional safety had become one urgent and critical issue during the COVID-19 pandemic in all of our health systems. WHO and we concurred that the theme 2020 had to be 'Health Worker Safety, a Priority for Patient Safety'.

GPC 2020 was IAPO's first fully digital congress with a record number of 1300 registered delegates from 101 countries with 338 patient groups, who attended 26 sessions with 64 speakers from 28 countries. The full summary of the Congress was for the first time published in the BMJ: <https://bit.ly/3mxF9Cs>

The Congress issued a strong call to action urging WHO Member States to urgently engage expert patients in their structures, processes and decisions in co-creating patient-centred public health and shielding programmes. The full statement can be read here: <https://bit.ly/3mB8v2H>

#### *IAPO Member participation in GPC 2020*

IAPO Members were invited to showcase their best COVID-19 activities and achievements in supporting their patient communities. IAPO for the first time provided over USD\$ 15,000 in special grants for those organizations who have merited support for their work in this critical phase: Uganda Alliance of Patients' Organizations - UAPO (Uganda), Epilepsy Support Association Uganda (Uganda), Sharecare Ghana (Ghana), Patient and Community Welfare Foundation of Malawi - PAWEM (Malawi), Save Liver - SLAP (North Macedonia), Action Group for Health Human Rights and HIV/AIDS - AGHA (Uganda), Consumer Online Foundation (India) and National Community of Women Living with HIV in Uganda – NACWOLA (Uganda). You can learn more about the deserving awardee organizations here: <https://bit.ly/38j3wPe>

Also for the first time, IAPO engaged our film-makers to record for posterity what challenges some of our members were facing during the COVID-19 pandemic. This was facilitated by GiJong An from the Korean Alliance of Patient Organizations, who have instituted the Patient Shouting Café, a very important methodology of engaging patients, their healthcare systems, journalists and regulatory agencies in addressing patient harm, patient safety and patient experience issues. You can see how the Patient Shouting Café works in practice here: <https://bit.ly/2Ko6jPb>

#### **2nd Asia Pacific Patients Congress**

The 2nd Asia Pacific Patients Congress was held as IAPO's second fully digital congress on 3-4 December 2020 with over 3000 registered from 66 countries with 298 patient groups, who attended 20 sessions with 66 speakers from 16 countries. The Congress aimed at bringing together patient experts and health stakeholders including researchers, nurses, health financiers, regulators, health service providers and pharmaceutical industry representatives to map out how we can all harmonise and align our agendas with national health policies and plans on Universal Health Coverage in the region.

To learn more about the Congress, please visit: <https://bit.ly/3axRPGX>. To view the session recordings, register for free and access the auditorium via this link: <https://bit.ly/3pdz3sQ>

#### **COVID-19 activities**

##### *IAPO COVID-19 statement*

IAPO released an official statement on COVID-19 in April posted on our newsletter, website and on all social media platforms. The statement called for a new COVID-19 Patient Engagement Collaborative Framework that puts patient experts at the heart of all COVID-19 related responses and measures: <https://bit.ly/2KHaTYL>

##### *IAPO's COVID-19 resources hub*

To support our members, partners and the grater global health community working to bring this outbreak to a close, we created a web page on IAPO's website to support the distribution of expert and relevant information and share best practices as part of our responsibility as a coordination and cooperation organization:

<https://bit.ly/2WBJoCx>

The hub has been the most visited page on our website with over 327 people sharing it on various social media platform. The initiatives on this page have also been shared on our newsletter and social media accounts. We are continually mapping relevant information and updates as it is published for inclusion on the page.

#### *IAPO Members' response to COVID-19*

We created a web page on the IAPO website to showcase a summary of IAPO members' response activities to fight the COVID-19 pandemic and support patients worldwide: <https://bit.ly/2KmYQQg>

#### *IAPO Member Stories on COVID-19*

This is an article series where IAPO members shared their stories on how the pandemic is impacting their work as well as their efforts to continue supporting patients during the pandemic. The series was promoted on IAPO's monthly newsletter and is available on the IAPO website here: <https://bit.ly/3rhmUon>

#### *WHO Information Network for Epidemics (EPI-WIN)*

IAPO supported the WHO in fighting the COVID-19 infodemic through being part of the newly formed WHO Information Network for Epidemics (EPI-WIN). The forum exists with the aim of using a series of amplifiers to share timely, accurate and relevant information to all.

### **Stakeholder engagement with partners**

#### *Upjohn (now Viatris)*

Twining programme on stroke in Asia: IAPO developed a twinning programme on stroke in Low and Middle Income countries (LMIC) located in the Asia-Pacific region, Middle East and Latin America.

Survey of patient experience of non-communicable diseases (NCDs) and COVID-19: This survey is a joint proposal with NIHI (National Institute of Health and innovation, Auckland, FIP (International Pharmaceutical Federation), WONCA, and IAPO, where our members in LMICs helped collect data from patients and caregivers to understand the true impact of the pandemic on NCD care.

#### *Voices of Safety - World Patient Safety Day 2020 storytelling campaign*

In partnership with BD, IAPO scoped patient stories for our joint storytelling campaign on patients' experiences related to healthcare systems safety to mark World Patient Safety Day 2020 on 17 September. You can watch the campaign videos here: <https://bit.ly/3h87azn>

#### *Union for International Cancer Control (UICC)*

IAPO joined UICC and its over 1200 members from more than 170 countries. UICC is the world's leading international cancer organization. UICC's activities are shaped by the World Cancer Declaration which sets out a framework to help reduce the global cancer burden by 2025, including through the adoption of the 2017 Cancer Resolution.

#### *Global Self-Care Federation*

IAPO worked with the Global Self-Care Federation to launch their Self-Care Readiness Index Consumer Survey among our network through our newsletter, website and social media. We have also marked the International Self-Care Day on 24th July in collaboration.

#### *Global Coalition for Circulatory Health (GCCH)*

We collaborated with GCCH through the COVID-19 webinars series in collaboration with the International Council of Nurses, World Organization of Family Doctors, World Federation of Public Health Associations and WHO. Under the theme 'Joining forces to fight COVID in people with circulatory conditions', IAPO represented the patient view on circulatory risk factors and outcomes associated with COVID-19.

#### *Antimicrobial Resistance Patient Advocacy Group*

Health First Europe launched the first European patients' advocacy group on AMR, which aims to raise awareness about antimicrobial resistance and to help reduce antibiotic misuse in Europe. The AMR patient advocacy group includes several national patient associations from across Europe, including IAPO members Fondazione The Bridge (Italy), Save Liver Association for Patients – SLAP (Macedonia), Pelvic Pain Support Network (EU), Malta Health Network (Malta) and The Patients Association (UK).

#### *International Federation of Psoriasis Associations (IFPA)*

As part of IFPA's webinar series in 2020, Kawaldip Sehmi, IAPO CEO, spoke at a webinar in October about IAPO's role in the resolution on Global Action on Patient Safety and how other patient associations can use it in their work.

#### *Fondazione The Bridge (FTB)*

Kawaldip Sehmi, IAPO CEO, wrote an article for the FTB newsletter in June about the importance of working in a network and how to manage the dialogue between patient associations. Read the article here:

<https://bit.ly/2Kln4L0>

#### *Global Alliance of Sickle Cell Disease Organisations (GASCDO)*

We had a collaborative meeting with GASCDO to rethink healthcare system strengthening to reduce the burden of sickle cell disease in underserved populations. This will be followed up in 2021.

### **IAPO Members survey**

IAPO conducted a survey to help identify ways of strengthening collaboration among IAPO members' network and ensure we prioritise our resources and continue to respond to our member organizations' priorities and needs throughout and beyond the pandemic. Results to be launched in 2021.

### **Communications**

**Newsletter:** Our monthly newsletter reaches out to over 5900 subscribers and has covered the COVID-19 pandemic news and information. It was very inspiring to see that over 30 patient organizations submit high quality articles on various aspects of healthcare globally, especially on how COVID-19 affected them. We are encouraging more patient organizations to submit articles for 2021.

**Twitter:** [@IAPOvoice](https://twitter.com/IAPOvoice) and [@PatientSolidarityDay](https://twitter.com/PatientSolidarityDay)

**Facebook:** We operate [IAPOvoice](https://www.facebook.com/IAPOvoice), [International Alliance of Patients' Organizations](https://www.facebook.com/InternationalAllianceofPatientsOrganizations), [African page and Patient Solidarity Day](https://www.facebook.com/AfricanPageandPatientSolidarityDay)

*Website:* Continues to be the main focal point for IAPO's dissemination and communications activities. We have seen an increase in number of page views: with over 100,000 page views in 2020 compared to 92,154 in 2019. [www.iapo.org.uk](http://www.iapo.org.uk)

## **Drive research processes and development of evidence base for patient centred-universal health coverage**

### **IAPO Scientific Advisory Board**

IAPO has set up a new Scientific Advisory Board to support the organization in its scientific programme in ensuring that patients have access to quality safe and evidence based healthcare. The inaugural Scientific Board and its membership can be found here: <https://bit.ly/38scZ6L>

### **Metrodora Award – recognising outstanding women achievers in science and health**

IAPO in partnership with Pfizer Upjohn (now Viatrix) and the Patient Academy for Innovation and Research (PAIR) introduced the first international Metrodora Awards to empower and recognize women leaders who are delivering positive changes in the care and management of non-communicable diseases (NCDs).

Metrodora was a Greek physician who lived between 200 to 400 CE and wrote the first known medical text to be authored by a woman. By studying and working on all aspects of women's health, she defied traditional gender roles during a time when women physicians were limited mainly to childbirth and obstetrics. Among many innovations, she pioneered surgical treatments for breast and uterine cancers – a legacy that has influenced throughout history.

IAPO, for the first time, undertook a consultation with patient organizations to nominate women scientists who patients thought were most deserving. IAPO in acknowledging and thanking these scientists awarded them over USD\$ 15,000 in honorariums. 2020 winners can be seen here: <https://bit.ly/2KKNZzH>

### **IAPO Patients for Patient Safety Observatory**

IAPO has established the IAPO Patient for Patient Safety Observatory (P4PS Observatory), a single-point global platform for gathering and analysing patients' expertise and experience that would feed into the national, regional and global policies aimed at improving safety and quality of care for patients and by the patients.

The reason why P4PS Observatory was formed was because patient harm has become a great public health problem, and it now requires expert patient oversight and co-creation. In order to do this, the P4PS Observatory will put patient led research into practice, and patient experience back into research. Patient harm not only causes great suffering, injury and death, it also erodes public trust in healthcare systems and costs billions of USD to address compensation and fines. The WHO Director General in his report and Resolution WHA 72.6 May 2019 Global Action on Patient Safety has asked every WHO Member State to produce plans to implement this resolution in the global consultation WHO Flagship "A Decade of Patient Safety 2020-2030": <https://bit.ly/2KFN1Vg>



### **Patient Academy in Innovation and Research (PAIR) collaboration Asia-Pacific**

IAPO is participating in the Asia-Pacific region to improve the quality of patient advocacy. The Patient Academy for Innovation and Research is set-up to develop and maintain capacity amongst patients across the globe, in an effort to enable them to engage with their health-systems in a more meaningful and strategic manner. Thus better equipping them to care for themselves and others, by framing their experience with an evidence-based expertise and share with other patients who suffer from the same or similar conditions and diseases. Learn more about PAIR here: <https://bit.ly/3nzYr02>

### **ISPOR - The Professional Society for Health Economics and Outcomes Research**

Ratna Devi, IAPO Chair was part of the Program Committee of the virtual ISPOR Asia Pacific 2020, themed 'Next Generation Healthcare in Asia Pacific: Where Technology Meets Patients to Improve Care'. The event offered a robust scientific program focused on in-depth studies of the current state of Health economics and outcomes research in the region. Healthcare is being transformed rapidly and dynamically with the rise of cutting-edge technologies that are providing patients with life-changing or curative benefit.

### **ISQUA – United to preserve antimicrobials - A joint call for action**

Along with the International Hospital Federation, the International Society for Quality in Health Care, and the International Federation of Pharmaceutical Manufacturers and Associations we issued a joint statement calling for antibiotic stewardship and preservation. The statement also calls for the development of more innovative partnerships of healthcare providers, patients and the business sector to tackle the growing AMR threat while improving healthcare safety and quality worldwide.

### **Published research papers**

Cancer medicine: a missed opportunity: <https://bit.ly/3nJK3xB>

A narrative review of the patient journey through the lens of non-communicable diseases in low- and middle-income countries: <https://bit.ly/3rfUvPA>

Systemic solutions for addressing non-communicable diseases in low- and middle-income countries:  
<http://bit.ly/3pfdgh>

A patient's wish - hospitals that care: <https://bit.ly/3mJvfxE>

Role of active patient involvement in undergraduate medical education: a systematic review:  
<https://bit.ly/34yQz2x>

Mapping the patient journey towards actionable beyond the pill solutions for non-communicable diseases:  
<https://bit.ly/38usBXq>