

## **2015-2017 STRATEGY ACHIEVEMENTS**

### **Strategic objectives for 2015–2017:**

#### **1) Leading the patient voice on global healthcare issues**

IAPO will take the lead on identifying key issues in healthcare on which to advocate at all levels of decision-making. IAPO will undertake research, produce briefings and toolkits for its members, and ensure the patient voice is heard in global, regional and national fora. IAPO will speak out on these key issues with a clear voice and seek to make its voice strongest where it can have most impact.

#### **2) Advancing patient engagement**

IAPO will develop and disseminate models, drawn from our membership experience, of effective patient engagement at all levels of healthcare decision-making. IAPO will work to show how patient engagement leads to more effective healthcare.

#### **3) Empowering the global patient movement**

IAPO will build the ability of its members to understand the key healthcare issues identified, and advocate effectively and clearly. This programme will include briefings, resources, webinars, and opportunities for face to face sharing and learning from each other at events. IAPO will also strengthen its regional networks, recognising that each region will have different ways to develop, and will be led by members in each region to enable appropriate IAPO support. In addition, none of the work of IAPO or the delivery of its goals can happen without the organization itself being strong, sustainable and committed. This objective includes strengthening IAPO itself as a responsible global organization working to achieve its vision and mission.

**Achievements against strategic objectives.**

**1. Leading the patient voice on global healthcare issues**

**2015**

- Representatives at 4 WHO RC meetings: EURO, PAHO, EMRO & WPRO (3 members, 3 Governing Board members, 2 staff)
- Interventions submitted on relevant topics
- IAPO involvement in IMI Get-Real Starts. Funded through Innovative Medicines Initiative (IMI) and running from 2013 to 2016. **Objective:** To better understand how real-world data can be used to inform the decision making process that leads to the launch of new medicines. **IAPO-led work:** The primary objective is to facilitate IAPO Members and other patient groups' input into Get Real

**2016**

- ***The 7th Global Patients Congress took place at the Selsdon Park Hotel, London on 9-11 April 2016. 136 delegates from 40 countries came together to discuss how sustainable innovation can boost reach and impact.***
- **World Health Organization-Executive Board** Geneva-Jan 25-30, 2016. Jolanta Bilińska (Chair) and Hussain Jafri attended the event. **Reach:** 194 ministers of health and 160 NGOs. World Media live broadcast of NGO interventions. **Activity:** Networking and made a statement on the Framework of engagement with non-State actors. **Outcome:** EB resolution to continue IAPO's status as an NGO in official relationship with WHO.
- **World Health Assembly 69th** Geneva May 23-29 2016. Chair Jolanta Bilińska, Board Member Matthias Wienold and Hussain Jafri attended the event. Supported by Kawaldip Sehmi. **Reach:** 194 ministers of health and 160 NGOs. World Media live broadcast. **Activity:** Held three side-events and made three interventions: i) health of migrant and refugee patients, ii) health in sustainable development 2030 –patient focus on UHC, iii) health of patients during large scale emergencies and health system collapse (natural disasters and Ebola). **Outcome:** WHA acknowledges the principle that patient engagement is essential in decision-making on migration, large-scale emergencies and humanitarian health planning and relief. Patients are core to SGG 3.8 and UHC. Social media recognition that IAPO is the first patients'-group championing patients' engagement in humanitarian and relief planning.
- **UN General Assembly Summit** Pre-meeting Refugees/ Migrants health and welfare July 18 2016 (Physically Hussain Jafri) and 9th September 2016 remotely via Webex Link

Kawal dip Sehmi. **Reach:** UN Agencies and NGOs involved with refugees and migrants.

**Activity:** Informal interactive multi-stakeholder meeting on health of migrant, refugee and internally displaced patients at the United Nations, New York. **Outcome:** IAPO placed patient-centred approaches and seamless health care on the agenda of all humanitarian bodies dealing with refugee and migrant issues. Patients' right to health must be respected by all belligerent parties.

- **WHO Afro 66th Regional Committee** Addis Ababa Ethiopia 19 to 23 August 2016 Chair-elect Joshua Wamboga. **Reach:** 44 ministers of health and 40 NGOs. African Media live broadcast. **Activity:** Two interventions: i) health of migrant and refugee patients, ii) health in sustainable development 2030 –patient focus on UHC. **Outcome:** WHO Afro acknowledges the principle that patient engagement is essential in decision-making on migration, large-scale emergencies and humanitarian health planning and relief. Patients are core to SGG 3.8 and UHC. Social media recognition that IAPO is the first patients-group championing African patients' engagement in humanitarian and relief planning.
- **WHO SEARO 66th Regional Committee** 5-9 September 2016, Colombo, Sri Lanka Chair-Jolanta Bilinska and Board Member Bejon Misra. **Reach:** 12 ministers of health and 40 NGOs. South Asian Media live broadcast. **Activity:** Two interventions: i) health of migrant and refugee patients, ii) Access to patient-centred health and fitness programmes. **Outcome:** WHO SEARO acknowledges the principle that patient engagement is essential in decision-making on migration, large-scale emergencies and humanitarian health planning and relief. Patients are core to SGG 3.8 and UHC. Health and wellbeing programmes should be accessible to all. Social media recognition that IAPO is the first patients-group championing South Asian patients' engagement in humanitarian and relief planning.
- **PAHO and WHO Americas 68th Regional Committee** 26-30 September 2016, Washington, USA Board Member Migdalia Denis. **Reach:** 35 ministers of health and 80 NGOs. US and LatAm Media live broadcast. **Activity:** Two interventions: i) Resilient Health Systems ii) WHO Framework Engagement non-State Actors (Fensa). **Outcome:** WHO PAHO and Americas acknowledges patient-centric health systems are resilient health systems and that UHC needs health system strengthening. SDG 2030 Goal 3.8 attainment needs health system strengthening. WHO engagement of non-state actors from the NGO sector needs a light-touch engagement to encourage participation.
- **WHO Western Pacific 67th Regional Committee** 10-14 October 2016, Manila, Philippines Karen Villanueva (Manila PAPO) and 2 other Philippines member organizations from Manila were attending event. **Reach:** 29 ministers of health and 30 NGOs. Asian and Australian Media live broadcast. **Activity:** Two interventions: i) SDG 2030 and UHC ii) WPRO Emerging Diseases Strategy. **Outcome:** WHO WPRO acknowledges that patient-centric approaches are needed to (achieve?) the SDG 2030 Goal 3.8 attainment. WPRO needs to place patient best interest and engagement in emerging diseases strategy.
- **UN NGO Committee for Rare Diseases** inauguration in New York. 11 November 2016 Migdalia Denis and Durhane Wong-Reiger joined Anders Olauson, Agrenska Foundation, to bring visibility and understanding of rare diseases to the United Nations. **Reach:** UN and WHO policy makers and over 2000 patient groups. **Activity:** Live Stream debate to the

world. **Outcome:** IAPO recognised as a part of the global strategy on rare diseases at UN level.

- **Value for Money – HTA WHO Meeting, 12-15 July, Geneva.** The meeting aimed at discussing how to develop global guidelines on HTA. IAPO was represented by Antonio Ciaglia. **Reach:** WHO, global patients' organisations, international healthcare stakeholders. **Activity:** Antonio presented on challenges facing patients in HTA. **Outcome:** IAPO invited to take part in process of development of global guidelines on HTA.
- **WHO African Region WHO Global Dialogue Meeting NCDs and SDG 2030** Balaclava, Mauritius, 19– 21 October 2016, IAPO member Dalilah Kalla from Lupus Alert Mauritius attended two meetings on our behalf. **Reach:** 54 African Countries represented through 40 civil society organizations. **Activity:** Participated in two workshops. **Outcome:** IAPO now part of the African non-State actors' network and the regional Framework for the prevention and control of Non-communicable Diseases (NCDs).
- IAPO provided responses to policy consultation launched by **WHO** (medical devices), **EMA** (access to medicines), **Transcelerate** (informed consent).
- **WHO WRPO Technical Advisory Group** 1st meeting for the Universal Health Coverage Manila Philippines 12 Dec 2016 IAPO member Josef De Guzman President Psoriasis Philippines attended on or behalf. **Reach:** 28 WHO WPRO Member States and their National Health Authorities and over 20 NGOs in official relationship with WHO and other non-State Actors organizations. **Activity:** Participated in workshops and discussions on UHC to learn from each other and work together, along with distinguished experts and other advisers, to identify priorities for the way forward. **Outcome:** IAPO now an official member of the WHO UHC Technical Group.
- **IAPO finished the patient research stream within GetReal in December 2016..** We developed a wide range of research activities with the aim of exploring patient acceptability of pragmatic trials and will be sharing this in 2017 with our membership via peer-reviewed papers and capacity building workshops at regional meetings to develop their awareness, capacity and efficacy to effectively engage in clinical research. <https://http://www.imi-getreal.eu/>
- IAPO has started his work in **IMI-PREFER**, an IMI-funded project which is currently in its first year. IAPO is working in close collaboration with other patient organisations (European Cancer Patients Coalition, European Patients Forum, Muscular Dystrophy UK) within the Patient Advisory Group (PAG) with the aim of providing meaningful input into the research team as to how to best collect, analyse, and use patient preferences in the medicines development process. IAPO is leading the workstream on methodology <http://www.imi-prefer.eu/>

## **2017**

- **World Health Assembly (Geneva, 22-31 May).** Being in an official relationship with the World Health Organization, IAPO was able to submit three comments on items of the official agenda of the World Health Assembly (WHA): Health emergencies (Agenda item

12.1); Donation and management of blood (Agenda item 13.2); Prevention and control of non-communicable diseases (Agenda item 15.1).

- In addition, IAPO held **6 side-events** co-hosting with a number of State and non-State Actors and our Industry Partners on important topics
- **Biotherapeutics & the next 70 years:** Delivering on their potential for patients globally, 23 May 2017, International Red Cross and Red Crescent Museum. Co-hosted by IFPMA (International Federation of Pharmaceutical Manufacturers and Associations) and IAPO, this event looked at the current issues of access and the variation in regulatory regimes in the approval of biosimilars (especially within Latin America). It brought together the International Federation of Pharmacists (IFP), prescribers, payers and patients to discuss the practice of switching and substitution between the originators and their biosimilars and the impact on the public budget and public health (patient safety pharmacovigilance). The take home messages were:
  - Biotherapeutics have transformed modern medicine through innovative and targeted therapies;
  - They have transformed lives of patients with chronic conditions (e.g. diabetes Type1);
  - Brought relief and reduced severity of symptoms for many rare conditions;
- **Displaced people with chronic conditions** – How to tackle the pandemic on the move, 24 May 2017, Musée Ariana. Co-hosted by IAPO, the Kenya Red Cross Society, Novartis and Novo Nordisk, this event debated the burden of noncommunicable diseases in displaced populations and the specific health challenges they face. It called upon actors from all sectors to share experiences and ideas on how to address the unmet needs. Multi-stakeholder partnerships and innovative financing models are needed to cope with the situation at hand. Joshua Wamboga our chair-elect spoke about South Sudan and its refugee population in Uganda and the impact on a struggling health system.
- **Access and care of patients with polychronic conditions:** An expert dialogue meeting, 24 May 2017, Restaurant Vieux Bois. Co-hosted by TEVA and IAPO, this event convened experts on the issues of patients with polychronic conditions, aspiring to unite the health care, policy and patient communities to address siloes between sectors and align policy agendas; highlighted the interconnections between the major global risks in the context of sustainable development goals 3 and the post-2015 development agenda, with particular focus on people suffering from polychronic conditions; and establish synergistic opportunities in polychronic, specifically highlighting 'what works' in the co-benefits approach to advance sustainable development and reducing risks and enhancing effective management of polychronic conditions. IAPO Board Secretary Penney Cowan launched the International Pain Awareness Month (September each year) in the occasion. Pain management is often conducted within polychronic disease management settings.
- **Addressing sepsis - the unrecognized number one cause of preventable deaths from infection / WHA Resolution A70/13**, 24 May 2017, Domain de Penthes. The dialogue, co-hosted by the Global Sepsis Alliance (GSA), the German Ministry of Health and

IAPO, was shadowing the recommendation of the WHO Executive Board to the 70th World Health Assembly to adopt a resolution WHA A70/13 - Improving the prevention, diagnosis and clinical management of sepsis that urges member states to develop training for all health professionals on infection prevention and patient safety. The meeting heard from patients and carers who called to highlight and help in understanding that infections which may lead to sepsis can often be prevented through appropriate hygiene, access to vaccination programs, to improved sanitation and water availability. The Resolution was adopted unanimously.

- **Global heart health and the road to 2025: Supporting a heart healthy agenda for the age of longevity**, 24 May 2017, InterContinental Hotel. This event was co-hosted by the World Heart Federation, DEVEX and IAPO, and was supported by Novartis. The event acted as a platform to share new data from 'Global Heart Health: Evaluating Efforts to Promote Healthy Hearts', a comprehensive report and scorecard of country progress in heart health, created by The Economist Intelligence Unit. A panel of health and innovation experts with Bejon Misra, our Board Member from South Asia, discussed where countries stand on the road to reducing premature mortality due to cardiovascular diseases by 2025. Experts will highlight the major challenges they face and discuss the available opportunities to unleash innovation in disease prevention, management and treatment in an ageing world.
- **Safeguarding blood safety for the multi-transfused patients**, 26 May 2017, UN Headquarters. Organized by IAPO and the blood and blood product using patients' organizations Thalassaemia International Federation (TIF), World Federation of Hemophilia (WFH), International Society of Blood Transfusion (ISBT), Worldwide Network for Blood & Marrow Transplantation (WBMT) and International Patient Organisation for Primary Immunodeficiencies (IPOPI) to enhance discussion on the WHA Resolution A70/19 - Principles for global consensus on the donation and management of blood, blood components and other medical products of human origin. The event focussed on raising discussion on blood safety for the multi-transfused patients and the patient perspective on the principles of global consensus on donation and management of blood and blood products. Multi-transfused patients are exposed to more risks from infections and adverse immunological response after a mismatched blood transfusion than any other blood recipients. Giving blood is like giving medication and the Medication Without Harm-the 3rd Global Patient Safety Challenge offers some systemic issues we need to address to strengthen patient safety in blood donations and transfusions.
- **IAPO supported a rapid mapping survey led by the WHO Patient for Patient Safety Geneva Office** with its WHO Country Offices on mapping national patient safety strategies and the existence of national patient safety institutional, legal and the policy and practice framework. The CEO provided support on the NHS Patient Safety Agency and the NHS policy framework lessons learnt. WHO has produced a draft landmark map of what is in place in each country and shared this with us. We are taking this work forward and have produced our own mini-survey to assess what our members are doing (pending release).
- IAPO took part and actively contributed input in to the WHO consultation on its newly released Framework of Interaction with **Non-State Actors (FENSA)**, to a WHO

consultation on the prequalification programme for similar **biotherapeutics products**, and a WHO consultation on the **WHO 13<sup>th</sup> Programme 2019-2023**.

- IAPO continues its work within the **Patients' and Consumers' Working Party** aimed at enhancing patient engagement in medicines development and appears in **EMA's list of European Expert**, enabling us to participate in specific initiatives concerning document review and scientific advice. Kawaldip Sehmi attended PCWP roundtable on improving messaging and naming biosimilars and two TCs to re-write a health professional fact sheet.
- **IMI-GetReal** has officially ended on 31 March 2017. The consortium is back at work to apply for an IMI exploitation call so as to be able to continue the work that has been carried out within the consortium. Some of the consortium's key outputs in 2017 to which IAPO has contributed include:
  - Real-world evidence navigator: Putting real-world healthcare data to work
  - PragMagic: Pragmatic Trial Resources
  - Online course: "Real-World Evidence in Medicine Development"
  - Journal articles:
    - Welsing, P.M., Oude-Rengerink, K., Collier, S., Eckert, L., van Smeden, M., Ciaglia, A., Nachbaur, G., Trelle, S., Taylor, A., Egger, M., Goetz, I. (2017) "Outcome selection and measurement in pragmatic trials". *Journal of Clinical Epidemiology*.
    - Oude Rengerink, K., Kalkman, S., Collier, S., Ciaglia, A., Worsley, S.D, Lightbourne, A., Eckert, L., Groenwold, R.H.H., Grobbee, D.E. Irving, E.A. (2017) "Participant eligibility, recruitment and retention in pragmatic trials". *Journal of Clinical Epidemiology*.
    - Mira G. Zuidgeest | Paco Welsing | Ghislaine van Thiel | Antonio Ciaglia | Rafael Alfonso-Cristancho | Laurent Eckert | Marinus J.C. Eijkemans | Matthias Egger (2017) "Pragmatic trials: defining questions, choosing comparators, allocating treatments". *Journal of Clinical Epidemiology*.
    - Brice, C., Isaac, C. Jonsson, P. Thwaites, R., Ciaglia, A., Ahsan, A., King, E., O'Brien, R., Buysse, B. and Kim, J. (forthcoming), "Patient-Powered Research Networks for Relative Effectiveness Research" on behalf of the GetReal Consortium. <https://www.imi-getreal.eu/Publications>
    - GetReal editorial on *Journal of Comparative Effectiveness Research*: Makady A., Stegenga H., Ciaglia A. et al on behalf of GetReal Work Packages 1 & 4 Practical Implications of Using Real-World Evidence (RWE) in Comparative Effectiveness Research: Learnings from IMI-GetReal, *Journal of Comparative Effectiveness Research*.
- **IMI-PREFER**. IAPO is part of the research consortium "IMI-PREFER", a 5-year research project aimed at exploring effective ways of incorporating patient preferences in the drug development process. The project is in its first year. IAPO is working with other patients organisations (European Cancer Patients Coalition, European Patients Forum, and Muscular Dystrophy UK) in the Patient Advisory Group. In particular we are leading the work stream on methodology.
- IAPO has been added to the NHS **National Institute for Health Research** pool of reviewers.
- IAPO and The **Economist Intelligence Unit** collaboration is progressing on a research proposal on the gap between legal consent and informed consent.
- **International Forum Safe Online Pharmacies New Delhi India 1-2 March 2017**  
Alliance for Safe Online Pharmacies (ASOP Global) brought together 160 key international stakeholders and local India partners for "Patient Safety and Access to Safe Online Pharmacies," an international forum in New Delhi, India.



Forum speakers included representatives from the Government of India (GoI) officials; India Consumer Online Federation; U.S. Food and Drug Administration (FDA); U.S. Pharmacopeial Convention; Great Britain; Indonesia; France; INTERPOL; the National Association of Boards of Pharmacy (NABP); International Alliance of Patient Organizations (IAPO); International Institution of Research Against Counterfeit Medicines (IIRACM); PhRMA; Pharmaceutical Security Institute; Partnership for Safe Medicines (PSM) India Office; Digital Health Platform (an association of Indian Internet pharmacies); the U.S. Embassy; and WHO SEARO and WHO SERO Office.

## **2. Advancing patient engagement**

### **2015**

- Attendance & three panel presentations at HTAi International conference in Oslo, June 2015
- Book to be published on patient involvement in HTA 2017 – IAPO invited to contribute, two abstracts submitted – published in **2017**  
<http://www.springer.com/gb/book/9789811040672>
- Invite to and presentation at WHO expert meeting on supporting member states on developing HTA for UHC and reimbursement

### **2016**

- **Prince Mahidol Award Conference & NICE Intl-priority setting** Thailand Jan 2016: Ryan Lee (NICE IAPO Designate) & Kawaldip Sehmi. **Reach:** Health Ministers from 26 SE Asian Countries and 1200 delegates from global public health and patient advocacy. **Activity:** Joint presentation with NICE Int on patient group engagement and embedding in HTA process, having permanent patient presence on NICE International and national HTA boards. Participation in WHO workshop and session with DTA on Quality and Compassion in UHC. Sharing a panel with Sir Marmot on health inequality and patient engagement. **Outcome:** Our expertise on patient involvement in HTA recognised and our presence in the region acknowledged.
- **Universal Health Coverage Annual Financing Forum** April 14-15 2016 Tele-conference Kawaldip Sehmi. **Reach:** World Bank UHC Forum (120 key health finance stakeholders). **Activity:** Advocated in panel discussions that patient-centred UHC critical for all. IAPO UHC principles promoted. Advocated that a patient-centred UHC is core to achieving sustainable development goals 2030. Financing alone is not enough. **Impact:** Acknowledgement that patient-centred UHC central to SDG 203).



- **Global Forum on Incontinence Berlin Germany April 29 2016 Panel Kawaldip Sehmi CEO. Reach:** 250 State and non-State Global Stakeholders involved in Continence Care. **Activity:** Presentation and panel on patient-centred continence care. Devices, care products and care should be acceptable and patient-centred. **Outcome:** IAPO interest in patient-centred continence care acknowledged by all. Patient-centred continence care touches many disease groups and ages, not only elderly. Products must be acceptable and fit for young active patients too.
- **European Conference on Rare Diseases and Orphan Products** May 27 2016 Edinburgh Panel Durhane Wong-Riegar and Kawaldip Sehmi CEO. **Reach:** 800 participants and 86 patient organizations involved in rare diseases. **Activity:** Panel-chair on advocating for a public health response on rare diseases at the international level. **Outcome:** IAPO leadership in rare diseases and orphan drugs in low and middle income countries acknowledged.
- **State of Oncology in Africa** Report Launch and iPRI National Cancer Institute's Directors Meeting July 11-13 2016 Jolanta Bilińska and Joshua Wamboga. **Reach:** 50 directors of National Cancer Institutes from low and middle income countries. 20 Oncology organizations and national Ministry of Health Agencies. **Activity:** Jolanta advocated Patient Centred Oncology a priority. Joshua expanded on oncology in Africa. Uganda's only radiotherapy machine is not working. **Outcome:** IAPO leadership in patient-centred oncology low and middle income countries acknowledged. Professor Boyle may collaborate with us on an African project.
- **FIFARMA meeting Panama City** July 26-27 2016. Latin American Pharmaceutical Manufacturers-Kawaldip Sehmi. **Reach:** 80 Pharmaceutical heads in Latin America. **Activity:** Presented our plan as to how we can collaborate with FIFARMA to benefit patients' in LATAM. **Outcome:** Latin American funding strategy and country cluster workshop idea developed. November launch opportunities.
- **The BIO International Convention (BIO)** FIFARMA meeting 6-9 June 2016. **Reach:** Attracts over 15,000 biotechnology and pharma leaders. **Activity:** Held a booth in Patient Forum Arena and intensive networking to discover new opportunities and promising partnerships with a wide spectrum of Biotech firms. **Outcome:** Opened dialogue with a number of organizations on biotherapeutics. Biosimilars tool kit update funding secured.
- **Health of 1.2 billion people 11th National Quality Conclave**, Quality Council of India and Indian Alliance of Patient Groups (IAPG) Roundtable 18-20th August 2016, New Delhi, India Bejon Misra and Matthias Wienold. **Reach:** Over 200 allopathic medicine and traditional aryuvedic treatment quality regulators and health policy makers in India. **Activity:** Led seminars and workshops on Quality of Care in UHC. **Outcome:** IAPO recognised as a patient leader in UHC quality issues
- **Association for Medical Education in Europe (AMEE) International Congress**, Workshop Co-Chair and speaker 29-30th August 2016 Barcelona, Spain Matthias Wienold and Stijntje Dijk IFMSA Liaison Officer for Medical Education. **Reach:** Over 3200 delegates from academia, industry and other NGO sectors engaged in medical education. **Activity:** Led seminars and workshops on Patient involvement in teaching and the medical

curriculum. **Outcome:** Patient centric medical education curriculum recognised as a policy issue and IAPO as a leader in developing it.

- **1st World Sepsis Congress** Online Workshop Matthais Wienold led inaugural online Seminar marking WSD 2016. **Reach:** Over 8000 patients, health care professionals and other stakeholders online. **Activity:** Led seminar on sepsis and challenges of patients and families. **Outcome:** IAPO recognised as the patient group with a sepsis care interest.
- **World Health Summit, Berlin Germany 10th Oct 2016 Panel.** The Contribution of Biologic Medicines to Public Health Matthias Wienold Co-chair and Speaker: and Durhane Wong-Rieger. **Reach:** Over 15000 participants includes ministers of health, health policy makers and patient organizations. **Activity:** Matthias Wienold co-chaired the panel on biotherapeutic medicines. **Outcome:** IAPO recognised as opinion leader and patient voice on biotherapeutics.
- **Think Health Romania's Health Conference** 13th October 2016 Board Member Androulla Eleftheriou attended this event in Romania. **Reach:** Nearly 100 Central and Eastern European Health Policy Makers. **Activity:** Participated in CE Europe Health Strategy. Live stream of debates and workshops. **Outcome:** Improved IAPO standing in Central and Eastern Europe.
- **Pre-ICDRA at International Conference of Drug Regulatory Authorities** Cape Town 27th Nov-29th Nov 16. **Reach:** 100 National Medicines Regulatory Authorities Present, including the 54 African NMRA and over 50 NGOs in official relationship with WHO and other non-State Actors organizations. **Activity:** Participated in one side-meeting and two workshops on patient engagement in strengthening and harmonising medicines regulation, especial access to biotherapeutics. **Outcome:** NMRAs recognise IAPO as a representative patient body that they can engage with in strengthening and harmonizing medicines and health device regulation. African NMRAs, Regional Economic Bodies and non-State actors aware of IAPO's patient-centric approaches.
- Novo Nordisk is promoting a collaborative project that will engage all pharmaceutical partners to set-up a web portal that will use a 'Trivago Style' algorithm that will highlight all the most important patient-centric health literature, clinical trials and **opportunities for patients to engage with national research programmes.**

## **2017**

- Migdalia Denis, IAPO's Board Member, attended **FIFARMA's Capacity Building Strategy** meeting in Miami. The meeting aimed at gaining understanding of the current regional and in-country needs of Patient Advocacy Groups, as well as of the efforts key stakeholders are doing. FIFARMA aims to develop a strategic plan for capacity building, based on capability levels of the Patient Advocacy Groups in Latin America.
- Jolanta Bilinska, IAPO Chair, Joshua Wamboga, IAPO Board Member, and Antonio Ciaglia, IAPO Policy Manager attended the **HTAi International Conference** in Rome, 20-22 June 2017 and presented on multiple topics related to patient engagement in HTA. **Outcome:** IAPO continues its work in HTAi's patients and citizens working group.

- IAPO signed an MOU with the The International Prevention Research Institute (**iPRI**) to mark the World Cancer Day

### **3. Empowering the global patient movement**

#### **2015**

- Launch of our online platform on Biologic and Biosimilar Medicines - [iapoamericas.org](http://iapoamericas.org). Presented at the Bio Convention in Philadelphia in June.
- **Fifth Regional Latin American meeting** with a multi-stakeholder seminar and capacity-building workshops held in Panama City in August. The meeting including capacity building sessions on generating evidence to legitimate advocacy, alongside a multi-stakeholder session at which innovation and regulation from a patient-centred perspective were discussed.
- **Patient Solidarity Day.** Thousands of people across the world joined together to celebrate Patient Solidarity Day on 5 December 2015. 108 organizations across 32 countries declared that healthcare is a human right. The campaign reached over 100,000 people via social media and dozens wrote articles and blog posts to mark the occasion.
- The African Regional Office for the World Health Organization (WHO AFRO) officially supported Patient Solidarity Day and the Western Pacific region for WHO wrote a letter of endorsement
- IAPO formalises the relationship with Alianza Latina by signing a Memorandum of Understanding.

#### **2016**

- **Latin American country cluster workshop:** IAPO held its first Latin American country-cluster workshop "Leave no-one behind" on 18-19 November 2016 in Bogota, Colombia. 40 stakeholders participated in a seminar on patient-centred Universal Health Coverage and access to Biotherapeutics. 26 patients' organizations from Colombia, Ecuador, Panama, Peru, and Venezuela actively engaged in capacity building workshops to

strengthen their advocacy skills, and receive a better understanding of patient-centredness and their role in facing the challenges and barriers to the availability, accessibility, acceptability, quality and safety of Biotherapeutics in the region.

- **Africa consultation:** IAPO carried out an in-depth consultation with its African members, in preparation for its regional activities in 2017. 81% of the membership participated in the consultation, which helped to highlight the challenges, priorities, capacity-building needs and stakeholder engagement activities of IAPO's patient advocates in Africa.
- **Patient Solidarity Day 3rd December 2016.** A very successful patient solidarity day on 3rd December 2016 that linked in with UHC Day 12th December 2016. Theme, logos and supporting material were prepared, to enable IAPO's members and other patient advocates to advocate globally, holding stakeholders to account on commitments made around universal health coverage. For the first year, IAPO used the social media tool, Thunderclap, which helped to build and maintain a strong online presence throughout the campaign.  
**Reach:** 172 groups from 44 countries participated. **Activity:** Walks, social media, health screenings and meetings. **Outcome:** Patient Solidarity Day being established in mainstream health policy advocacy. Report available online at our website: [iaipo.org.uk/highlights-patient-solidarity-day-2016](http://iaipo.org.uk/highlights-patient-solidarity-day-2016)
- The Chair and Migdalia Dennis represented IAPO at the **Alianza Latina** Conference in November 2016
- **EPF Conference on Patient Safety**, 7-8th November 2016. Speaker: Antonio Ciaglia, IAPO Policy Manager. **Reach:** EPF members, WHO Technical Officer. **Activity:** Antonio Ciaglia presented on IAPO's advocacy work in the field of patient safety. **Outcome:** IAPO invited to take part in EPF-led Task Force on patient Safety. IAPO represented by the Chair of the Board, Jolanta Bilinska.
- **EFCCA International Congress, 14-15 November 2016**, Brussels. Antonio Ciaglia represented IAPO. **Reach:** EFCCA members, EU policy makers and health professionals. **Activity:** Antonio took part in congress activities, including workshop on challenges facing patient organisations. **Outcome:** IAPO recognised as one of EFCCA's key partners.
- Our phase one of the joint survey on **patients', regulators', prescribers' and pharmacists' perspectives on biotherapeutics** (Biologic and Biosimilar) with IFPMA was completed by the Health Policy Partnership (London) in November 2016 and handed over to the Institute for Optimizing Health Outcomes to write up a report on. This report will be launched in Autumn 2017 and we will then continue developing capacity amongst Patients Organizations, Regulators, Physicians, Prescribers and Pharmacists to bring about patient-centricity approaches to the bio-therapeutics (biologics and biosimilars) regulation, clinical practice and prescription practice.
- **Cochrane Consumers Network, Colloquium in Seoul, South Korea, 23-27 October 2016.** The conference focused on evidence-based medicine, with workshops specifically exploring care-givers and carers. IAPO facilitated the participation of member, the **Korean Alliance of Patients' Organizations**, in the colloquium.
- **European Healthcare Industry Training: Compliance Certification Programme, Seton Hall Law School and Sciences Po, Barcelona, 16 November 2016.** IAPO

member, Acción Psoriasis, presented at a training session regarding interaction between patient organizations and the pharmaceutical industry. Drawing on IAPO's Consensus Framework for Ethical Collaboration, Anna Olivia, provided the patient perspective to the training programme's participants, which included legal, regulatory and compliance professionals and advisors working within the European pharmaceutical, biotech and medical device industries.

## **2017**

- Development of IAPO-industry collaborative projects (**Empowerment Toolkit and the Biosimilars Toolkit**) aimed at increasing patient advocates' knowledge as to how to develop cross-stakeholder collaborations in healthcare
- We are currently participating in the **EPF-led Task Force** on patient safety, represented by our Chair Jolanta Bilinska.
- **3rd African Regional Meeting**, held on 4th – 5th July 2017 in Entebbe, Uganda, the meeting brought together over 30 of IAPO's member organizations and collaborators, representing ten African countries. The meeting, which focused on the on-going African Medicines Regulatory Harmonization (AMRH) initiative, culminated in delegates making a united call for a patient-centred African Medicines Agency (AMA) in which patients are meaningfully engaged.
- **African programme development.** Following the regional meeting in Uganda, IAPO is working with members and other patient advocates in the region to lobby and influence decision-makers to ensure that patients are recognised as key partners in the African Medicines Agency. IAPO is seeking to formalise its relationship with the New Partnership for Africa's Development (NEPAD) through the form of a Memorandum of Understanding.
- **3rd Biennial Scientific Conference on Medical Products Regulation in Africa, 27 – 28 November 2017, Ghana.** The New Partnership for Africa's Development (NEPAD) invited IAPO to send a patient advocate from the region to represent the patient movement by speaking at a session on civil society engagement in harmonisation. This will be an opportunity to continue pushing the calls for patient engagement in the African Medicines Agency.
- **Alianza Latina Meeting, 26-27 October 2017, Rio de Janeiro.** Alianza Latina and IAPO Forum – Best practices for the Third Sector in health. The event will be held on 26-27 October in Rio de Janeiro, Brazil. IAPO will hold a specific session on the second day entitled 'Clinical Research in Latin America' to discuss the following topics: i) what are the rights and benefits of the patients who participate on clinical trials?; ii) the importance on considering the voice of the patients on the development of clinical trials; and iii) the clinical research being conducted in Latin America.
- **2<sup>nd</sup> TAG meeting, Universal Health Coverage meeting, WHO Western Pacific Region, 13-15 November 2017, Manila, Philippines.** After IAPO's successful representation at the 1<sup>st</sup> TAG meeting in 2016, IAPO will be represented by the Philippines Alliance of Patient Organizations for the 2<sup>nd</sup> convening on the topic.

- Antonio Ciaglia is representing IAPO in the core group of the newly launched **Rare Diseases International Advocacy and Policy Committee**. The committee was established in September 2017 and has already delivered an output (response to WHO consultation on 13<sup>th</sup> programme 2019-2023).
- **IAPO Research Unit** is moving on and its concept note, operational document, and strategy have been developed.
- **PRE - Patient Research Exchange**. We have now fully taken over this resource. The 'exchange' will form an important part of our Research Unit and its information dissemination strategy. We are inviting our pharma partners to submit articles and research results that could benefit our members. Patient Research Exchange's mission is to provide a platform that delivers high-quality information and enhances cross-stakeholder dialogue on how to best pursue and put in practice meaningful patient engagement in medical research.
- The **Member Engagement and Empowerment** plan. At the start of 2017, IAPO launched an engagement plan to facilitate members' engagement with IAPO's work. We focused on four overarching themes for the year, which were patient-centred healthcare, access, transparency and accountability and Empowerment (Patient Solidarity Day theme). Each month, we have focused on a sub-theme, exploring the issues through policy briefings (see further detail below), engagement with members internally and on social media, and through a thematic newsletter edition. By focusing in this way we have facilitated greater participation from IAPO's membership and wider network, for example through contributions to the monthly newsletter and networking between members.
- **The Policy Briefing Series**, which forms a key part of the Member Empowerment and Engagement plan, aims at providing IAPO members, partners and stakeholders with a systematic overview of how key global healthcare issues impact patients and the role patients can play in policy making and shaping. The briefings published to date cover topics such as Patient-centred healthcare, Patient Information and health literacy, High-quality access to care, Patient involvement in HTA, Patient safety, Medicines regulatory harmonization, Pain management, patient empowerment.
- In the first quarter of the Member Engagement and Empowerment plan, we held a webinar to develop the capacity of IAPO's member organizations, which **explored practical approaches for finding and assessing the most credible health evidence to help patient organizations to build a strong case when advocating for change. The speaker Fiona Morgan, a Systematic Reviewer and Lecturer at Cardiff University**, shared tips and tools on how to navigate the range of health evidence available to effectively assess the credibility and value of a source. She also presented strategies, techniques and tools for carrying out this assessment. To provide for IAPO's large membership in Latin America, we facilitated simultaneous Spanish translation.
- **IAPO has starting filming for a new empowerment initiative – the Patient Voice platform**. This will be an online space for members to highlight and share powerful stories on innovations in patient advocacy relating to the work of their organizations, that they can share with others in the network. It will act as a platform for sharing and

disseminating best practice in patient advocacy, as well as assisting networking and engagement between members and other stakeholders.

- **Patient Solidarity Day, Saturday 2nd December 2017**, will be centred on the theme “Globally Empowered Patients. Power Through Knowledge”. Earlier in the year, IAPO conducted a consultation with all members and stakeholders, asking for their suggestions for the upcoming day and all members had the opportunity to vote on the final theme. A PSD 2017 Grant Scheme was launched in September, which provides a small amount of financial support to members in their advocacy activities. These grants will assist members in holding activities, such as hosting seminars, conferences, marches and lobbying. Once again, we will use the social media tool, Thunderclap, to maintain momentum on the campaign.
- **Meet the Members** series. To encourage networking between members and to highlight the diverse and significant expertise evident among IAPO’s members, each month we have published a video interview with one of IAPO’s member organisations. This also acts as a platform for showcasing the work of members.
- **International Pain Awareness Month**. In September, IAPO dedicated the Engagement and Empowerment plan to International Pain Awareness Month, as led by the American Chronic Pain Association. The campaign gained traction from members and the wider network, securing engagement globally, notably from patient advocates in India, Australia, Bulgaria, UK, Ireland, Croatia, Venezuela. The IAPO secretariat also took part in the ‘Give a Squat 4 Pain’ element of the month, by posing for a ‘squat’ photo, which was posted on social media.
- **WHO 13th General Programme of Work 2019-2023**. IAPO conducted a survey with its members on WHO’s consultation 2019-2023 programme. An IAPO submission was made, reflecting comments from members in Uganda, Venezuela, Kenya and the Philippines.