



International Alliance of
Patients' Organizations

A global voice for patients

6th Global Patients Congress

Better access, better health:
A patient-centred approach to
universal health coverage



Congress Handbook

Macdonald Berystede Hotel, Ascot, UK • 29–31 March 2014



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6th Global Patients Congress

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Dear Congress Delegate,

It is my great pleasure, on behalf of IAPO's Governing Board, staff and the Congress Advisory Committee, to welcome you to the 6th Global Patients Congress. This is the global event for patient leaders and others working to improve healthcare systems. At an important time for global health, with increasing efforts towards improving access to health, this Congress will explore the theme **'Better access, better health: A patient-centred approach to universal health coverage'**.

The 6th Congress will bring together expertise and experience in how to build patient-centred healthcare globally and provides a platform for high-level policy debate, knowledge and skills-building as well as opportunities for networking and exchange.

The workshops and plenaries will build on activities and issues discussed during previous Congresses, for example the launch of the IAPO Declaration on Patient-Centred Healthcare, defining patient-centred healthcare from a patient perspective, at the 2nd Congress in 2006 and the focus of the 5th Congress in 2012 on how we measure the extent to which patient-centred healthcare is achieved around the world.

A key principle of patient-centred healthcare is access to healthcare, and according to IAPO's Declaration on Patient-Centred Healthcare, it must be safe and of high quality, universal (patients must have access to the healthcare services warranted by their condition) and tailored to patients' needs. These principles are central to the World Health Organization (WHO) definition of universal health coverage (UHC), with synergies between IAPO's work on patient-centred healthcare and global efforts to achieve universal health coverage. The Congress will explore how a patient-centred approach can address the factors that will lead to UHC and consider the patient's perspective.

The Congress Advisory Committee has supported the development of the Congress from the beginning of the process in May 2013 and has been a vital resource in ensuring that the needs of IAPO members, and other allies and stakeholders, are met. They have ensured that the agenda items are relevant, recommended speakers, supported fundraising activities and shared ideas and experiences from other conferences which aim to ensure this Congress is the best so far.

As IAPO Chair I look forward to meeting and working with you towards mutual aims over the coming days. The IAPO Governing Board and staff will be on hand during the Congress should you need support in engaging in the Congress.

Best wishes,

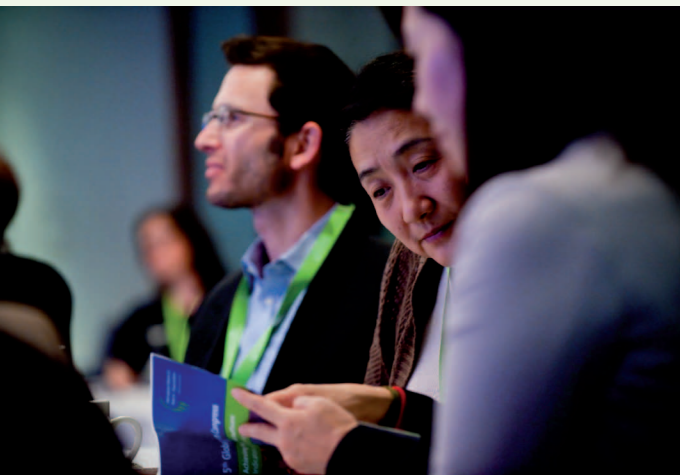
Kin-ping Tsang
IAPO Chair



Introduction to the Congress

"I regard universal health coverage as the single most powerful concept that public health has to offer. It is inclusive. It unifies services and delivers them in a comprehensive and integrated way, based on primary healthcare."

Dr Margaret Chan, WHO Director-General



Around the world, governments are realising the potential of universal health coverage to transform health systems and ensure access to healthcare for all. But what does universal health coverage mean and how can healthcare stakeholders work with patients to ensure that access to healthcare is patient-centred? With a theme of **'Better access, better health: A patient-centred approach to universal coverage'** this Congress will provide the opportunity to explore what universal health coverage means from a patient perspective and its potential to improve health for all.

The goal of universal health coverage is to ensure that all people obtain the health services they need without suffering financial hardship when paying for them.¹ This means that health systems must provide access to equitable, high-quality care which is

sustainably financed. The concept of universal health coverage shares some common elements with IAPO's definition of patient-centred healthcare, which highlights the importance of access to safe, quality and appropriate services, treatments, preventative care and health promotion activities, regardless of their condition or socio-economic status.

However, for universal health coverage to be truly patient-centred this definition needs to go further. No one is better placed than the patient to highlight unmet needs and to share best practice in the delivery of healthcare. It is therefore imperative that patients are involved in all decision-making relating to healthcare and have an active and empowered voice in policy development as more and more countries move towards universal health coverage.

The Congress is a unique opportunity for patient representatives and other stakeholders to come together to explore how quality in healthcare is defined, the future of patient empowerment and engagement and what patient-centred universal health coverage looks like? This year's Congress will mark the beginning of a journey that will define universal health coverage from the patient perspective.

An essential part of the Congress programme is the IAPO Member Only Day. This day has been designed to maximise the sharing of experiences between IAPO's member patients' organizations, through plenaries and interactive workshops. The day aims to maximise member learning, information sharing and networking to facilitate members to build their knowledge, partnerships, strengthen their advocacy as well as provide the opportunity to feed into IAPO's work at a global level. This year, members will engage in facilitated discussions which will lead to the development of a draft set of principles on universal health coverage.



¹ http://www.who.int/universal_health_coverage/en

Congress Sessions

The Congress programme is designed to stimulate discussion and debate and demonstrate the value of patient-centred healthcare and its role in improving access to healthcare. In addition to the plenary sessions there are three streams of breakout sessions, each of which focuses on one of the three pillars of universal health coverage: equity, quality and financing.

Equity Stream: To achieve better access, it is essential that patients have equitable access to the treatments they need. This stream will explore the current challenges to achieving equity in health systems, how more patients can access healthcare, how patient representatives are addressing these challenges, and what patient empowerment means in an ever-changing healthcare context.

Quality Stream: Expanding the provision of healthcare whilst maintaining a high quality of services is a challenge that all health systems must address if they are to achieve universal health coverage. This stream will examine what quality of care means from a patient perspective, share patient-centred initiatives and explore how quality in healthcare can be measured.

Financing Stream: Achieving universal health coverage requires sustainable financing mechanisms. This stream will explore the role of healthcare financing in times of financial constraint and look at how involving patients in decisions about health financing can lead to better value for money. It will share models of financing universal health coverage and the implications this has for patient care.

As well as the plenary and workshop sessions, there are many other formal and informal opportunities to build our networks, work together and share ideas. Please see pages 10–12 for more information on these activities.

About IAPO

The International Alliance of Patients' Organizations (IAPO) is the only global alliance representing patients across all disease areas and promoting patient-centred healthcare around the world. Our members are patients' organizations working at the international, regional, national and local levels to represent and support patients, their families and carers.

Vision

IAPO's vision is that patients throughout the world are at the centre of healthcare.

Mission

IAPO's mission is to help build patient-centred healthcare worldwide by:

- Realizing active partnerships with patients' organizations, maximizing their impact through capacity building
- Advocating internationally with a strong patients' voice on relevant aspects of healthcare policy, with the aim of influencing international, regional and national healthcare agendas and policies
- Building cross-sector alliances and working collaboratively with like-minded medical and health professionals, policy-makers, academics, researchers and industry representatives

Members

IAPO has over 220 members, representing over 60 disease areas and over 60 countries, in a network that connects over 4,000 organizations and represents an estimated 365 million patients worldwide. The impact of IAPO's voice is created by the diversity and breadth of members who drive our work towards patient-centred healthcare.



Acknowledgements

We would like to thank the many individuals and groups that have provided us with invaluable support in the development of the 6th Global Patients Congress. In particular we would like to thank:

Advisory Committee

- Orajitt Bumrungkulswat** Heart to Heart Foundation, Thailand*
- Carolina Cohen** Brazilian Leukemia and Lymphoma Society (ABRALE)*
- Yoram Cohen** Global Alliance of Mental Illness Advocacy Networks – Europe (GAMIAN)*
- Téa Collins** World Medical Association (WMA)
- Eric de Roodenbeke** International Hospital Federation (IHF)
- Androulla Eleftheriou** Thalassaemia International Federation (TIF)*
- Said El Kharrazi** Moroccan Federation Supporting People with Kidney Insufficiency and Organ Transplantation*
- Atibar Khan Fattal** Life Saving Organization for Afghanistan*
- Michael Kinyanjui** Africa Psoriasis Organization, Kenya*
- Brenda Myers** World Confederation for Physical Therapy (WCPT)
- Stephen Murby Wright** Consumers Health Forum of Australia*
- Mario Ottiglio** International Federation of Pharmaceutical Manufacturers & Associations (IFPMA)
- Nittita Prasopa-Plaizier** World Health Organization (WHO)
- Eva Maria Ruiz de Castilla Yabar** IAPO Secretary and Esperantra Peru*
- Rebekkah Schear** LIVESTRONG Foundation, USA*
- Dr Sophie Staniszewska** Patient and Public involvement and Patient Experiences, Warwick Medical School, UK
- Professor David Taylor** Professor of Pharmaceutical and Public Health Policy, University College London (UCL), UK
- Professor Jonathan Tritter** Professor of Sociology and Public Policy, Aston University, UK
- Kin-ping Tsang** IAPO Chair and Hong Kong Alliance of Patients' Organizations*
- Joshua Wamboga Magawa** The AIDS Support Organisation (TASO) Uganda*
- Jun Wang** Beijing Association of Alzheimer's Disease and Related Disorders, China*
- Matthias Wienold** European AIDS Treatment Group*

* IAPO Members

Event Coordination



Carol Stevenson

Event Coordinator
Director, Novus Marketing & Event Management
info@globalpatientscongress.org

novus

Carol has over 10 years of experience in managing events for the healthcare sector in the UK, Europe and the US. Carol became interested on a personal level in patient-centred healthcare when she was diagnosed with Adult-Onset Still's Disease in 2008, a rare chronic arthritic condition, so she is delighted to be working with IAPO on the Congress.

Since founding Novus in 2009, Carol also manages the annual conferences of the Patient Information Forum (PiF), the Chartered Institute of Librarians and Information Professionals (CILIP) Health Libraries Group and the National Cardiothoracic Benchmarking Collaborative (NCBC). She has a Master's with Honours in Latin and Classical Studies from the University of St Andrews, graduating in 2001. She became an elected Associate Member of the Chartered Institute of Marketing in 2010 and was shortlisted the same year for Best New Female Marketer in the CIM Women in Marketing Awards.

Carol is assisted onsite by her Novus colleagues **Kay Bonetti**, Delegate Manager, and **Carolyn Seaman**, Speaker & AV Manager.

The Health Programme of the European Union¹

IAPO would like to thank the European Union for awarding a conference grant for the 6th Global Patients Congress. www.ec.europa.eu/eahc/health



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Supporters and Partners

International Council of Nurses (ICN) • www.icn.ch

The ICN is a federation of national nurses associations, representing the more than 13 million nurses working worldwide.

International Hospital Federation (IHF) • www.ihf-fih.org

The IHF, established in 1929 in Atlanta, is an independent, not-for-profit, non-governmental membership organization based in Geneva and is constituted as an association, as defined in article 60 of the Civil Code of Switzerland. It is the unique international organization representing the decision makers leading the healthcare sector. It also includes representatives from major healthcare facilities and organizations linked up with the provision of healthcare.

Improving the health of society is our priority. To this end, we provide a unique environment that allows today's health leaders, policy-makers, regulatory authorities, and healthcare professionals to interact, share information and practices, and exchange ideas and experiences in order to be equipped with the tools necessary to provide maximum safety and high-quality service delivery, promote healthier living, and ultimately to shape the future of the global healthcare system.

IHF's vision is a world of healthy communities served by well-managed hospitals and health services. The mission is to:

- Support organizations in the promotion and delivery of healthcare
- Promote interaction among different health system stakeholders
- Share knowledge and experiences
- Support creation of new national hospital associations
- Disseminate evidence-based information
- Help hospital decision-makers define strategies

The IHF is a platform for knowledge exchange through international events, management training courses, information services, publications and consultations. We have developed Special Interest Groups in three major areas: healthcare executives, university hospitals and group purchasing.

IHF supports the development of workshops in various countries and we recently launched a course on management for healthcare managers. The focus is on both developed and developing nations and aims to facilitate the exchange between countries, organizations and individuals.

The IHF is in official relations with the World Health Organization. Technical partnerships exist with other key major stakeholders in the international health sector, including the Organization for Economic Co-operation and Development. Collaborative agreements have been established with international organizations such as IAPO, Health Promoting Hospitals, International Society for Quality in Healthcare and other major professional associations.

In 2014 the IHF will organise its 4th Hospital and Healthcare Leadership Summit, a members-only event, open to top-level decision makers from hospital and healthcare organizations and selected key regional and international healthcare leaders. The Summit represents a platform for peer-led debate. It is also an opportunity for high-level discussion with partners' organizations. The 4th IHF Leadership Summit will be held on 11–12 November 2014 in Seoul, Korea.

The 39th edition of the IHF World Hospital Congress will be held in Chicago, USA, on 6–8 October 2015.

¹ The content of this handbook represents the views of the author and it is his sole responsibility; it can in no way be taken to reflect the views of the European Commission and/or the Consumers, Health and Food Executive Agency or any other body of the European Union. The European Commission and/or the Executive Agency do(es) not accept responsibility for any use that may be made of the information it contains.

The IHF World Hospitals & Health Services Journal is published four times a year and provides a vehicle for publishing articles on broad topics of interest, not only to healthcare professionals, but also a broader readership interested in new and innovative thinking and trends in health systems. Most issues are on thematic areas such as University Hospitals, role of IT, and development in Asia.

International Pharmaceutical Federation (FIP) • www.fip.org

Founded in 1912, the International Pharmaceutical Federation (FIP) is the global federation of national associations of pharmacists and pharmaceutical scientists and is in official relations with the World Health Organization (WHO). Through its 126 member organizations, FIP represents and serves more than three million practitioners and scientists around the world.

Throughout its 100-year history, FIP's priorities have expanded both literally and figuratively to meet the needs and expectations of the profession in expanding healthcare services and integrating emerging scientific developments. Changes in pharmacy and the emergence of Pharmacy Practice as a cornerstone of the profession have led FIP to become globally visible for its advocacy on behalf of the role of the pharmacist in the provision of healthcare, while still maintaining its grounding in the pharmaceutical sciences.

In parallel, the membership of FIP has evolved to become the most extensive global pharmacy and pharmaceutical sciences network. This network is continuing to expand its presence and influence through partnerships with some of the world's leading healthcare, educational and scientific institutions.

FIP's highest organ is the FIP Council. In the Council, all national pharmaceutical associations (member organizations) and national pharmaceutical scientific associations (predominantly scientific member organizations) are represented and have voting rights. FIP's observer organizations, supra-national pharmaceutical (scientific) associations, also participate in the Council but do not have voting rights.

Both internal and external forces are steering the course of modern healthcare and in turn how each profession can best contribute to it. Recognising this fact, FIP has developed a new Vision, Mission and Strategic Plan with the goal of firmly integrating the Federation and those it serves in global healthcare decisions and actions. As such, the vision that FIP sets forth is that, wherever and whenever decision makers discuss any aspects of medicines on a global level, FIP is at the table.

FIP is enabled to succeed in this vision through the recognition and respect it gains through the fulfillment of its mission, which is to improve global health by advancing pharmacy practice and science to enable better discovery, development, access to and safe use of appropriate, cost-effective, quality medicines worldwide. Carefully developed strategic objectives and tactical approaches complete the tools needed for FIP to succeed in this endeavour, the ultimate result being increased patient safety, care and health.

At the Centennial of FIP in 2012 a declaration was signed by all FIP member organizations putting the patient in the centre: "As pharmacists and pharmaceutical scientists, we are committed to ensuring optimal outcomes from medication therapy through patient-centred care. We recognise that the health of patients and populations is compromised and the value of medicines is diminished when medicines are not accessible, are of inferior quality, or are used inappropriately."

World Confederation for Physical Therapy (WCPT) • www.wcpt.org

Founded in 1951, the WCPT is the sole international voice for physical therapy, representing more than 350,000 physical therapists worldwide through its 106 member organizations. The confederation operates as a non-profit organization and is registered as a charity in the UK.

WCPT believes that every individual is entitled to the highest possible standard of culturally appropriate healthcare delivered in an atmosphere of trust and respect for human dignity, and underpinned by sound clinical reasoning and scientific evidence. It is committed to furthering the physical therapy profession and improving global health through:

- Encouraging high standards of physical therapy research, education and practice
- Supporting the exchange of information between WCPT regions and member organizations
- Collaborating with national and international organizations

World Dental Federation (FDI) • www.fdiworldental.org

The World Dental Federation (FDI) serves as the principal representative body for more than one million dentists worldwide, developing health policy and continuing education programmes, speaking as a unified voice for dentistry in international advocacy, and supporting member associations in oral health promotion activities worldwide. Over the

years, it has developed programmes, initiatives, campaigns, policies and congresses, always with a view to occupying a space that no other not-for-profit group can claim.

FDI works at the international and national levels through its own activities and those of its members. FDI is in official relations with the World Health Organization (WHO) and a member of the World Health Professions Alliance (WHPA).

FDI seeks to achieve optimal oral health for all people across borders, uniting the world of oral health to harness the collective expertise and power of our members together with all sectors of society. As the profession's global and independent advocate, we champion disease prevention and oral health literacy and advance the ethics, art, science and practice of dentistry by stimulating and facilitating the exchange of information throughout the healthcare community.

FDI's membership includes approximately 200 national member associations and specialist groups from more than 130 countries. A non-governmental organization based in Geneva, Switzerland, FDI is governed by a General Assembly, with policy enacted by its Council and activities implemented through five standing committees comprising 60 volunteers from among its national member associations. Every year, some 300 delegates attend FDI's World Dental Parliament to debate and define the global future of dentistry.

FDI's long and distinguished history and accumulated experience in dental education, public health, and access to care make it a unique expert in the field and the only international organization in the field of oral health in official relations with WHO and other agencies of the United Nations. FDI's technical expertise is coupled with local knowledge and contacts through its vast worldwide network of dentists.

World Health Organization (WHO) • www.who.int

IAPO has been working with the WHO's Patients for Patient Safety Programme since 2005 and been in official relations since 2007. Since the first IAPO Congress in 2005, WHO has been actively engaged in contributing knowledge and expertise to enrich the Congress and promote patient engagement in service delivery, healthcare policy and systems. In 2014, WHO contributions to IAPO Congress include participation in the Congress's Advisory Committee, holding a WHO session on patient safety within the programme and WHO representatives presenting and participating in the Congress programme.

WHO Service Delivery and Safety

WHO launched the World Alliance for Patient Safety in 2004, which was renamed WHO Patient Safety in 2009. Since November 2013, the department has been known as Service Delivery and Safety (SDS). This is to reflect its expanded goal, which is "to increase access to safe, high-quality, equitable, people-centred, integrated health services". SDS will act as a 'centre of excellence' in the area of service delivery that is to be the core department leading on issues of safety, quality, care integration, people-centred care, community participation, patient and family engagement, non-commercialisation of donation of blood, organs and other therapeutic products of human origin and clinical procedures.

WHO Service Delivery and Safety provides a vehicle for international collaboration and action between WHO member states, WHO's secretariat, technical experts, and consumers, as well as professionals and industry groups. Patients are at the core of this work. The Patients for Patient Safety Programme (PFPS) has become a key player in the coordination of patient and family engagement, community participation and collaboration with civil society, including non-governmental organisations, in efforts to realise patient-focused and people-centred health services.

WHO Service Delivery and Safety Vision: "All people receive safe, high-quality, people-centred, integrated health services, at every interaction across the health services continuum."

World Medical Association (WMA) • www.wma.net

The WMA is a global federation of national member associations representing over nine million physicians in 106 countries. WMA strives to achieve the highest standard of medical education, medical ethics and patient care and to advance adherence to international human rights principles related to health.

WMA is one of the founding members of the World Health Professions Alliance (WHPA), which is a partnership of global organizations representing over 26 million physicians, nurses, pharmacists, dentists and physical therapists in 130 countries. The WHPA sets a standard of excellence of inter-professional collaborative practice at the global level through its joint advocacy for educational, legislative, and health systems changes that bring about and strengthen inter-professional partnerships.



Congress Information

Access to the Congress

Access entitlements

On Saturday 29 March 2014, the Congress is open for IAPO members only, who will have access to the Congress and the Congress exhibition for the duration of the event. All first-time member delegates are advised to register and attend the breakfast briefing at 08.00. If you do not wish to attend the breakfast briefing but are a member of IAPO, please register at 09.00.

Registration for all other stakeholders will open at 16.00 on Saturday 29 March 2014. The Congress programme and exhibition on Sunday 30 March and Monday 31 March 2014 are open to all delegates.

Please ensure that you are in your seat at least five minutes prior to the scheduled start time of each session and ensure that all phones, smartphones and electronic devices are switched to silent.

Badges

Admission to Congress sessions is strictly by badge only. Badges are printed in six different colours to help delegates with networking and also to differentiate the staff. The badge colours are:

- **Blue** – Delegate Member
- **White** – IAPO Governing Board Member
- **Yellow** – Sponsor
- **Black** – Exhibitor
- **Red** – IAPO Staff
- **Green** – Delegate Non-Member

First-time attendees will have a sticker on their name badges. Those who have attended in the past are encouraged to meet with and speak about their experiences of the Congress with newcomers.

In the interest of security, please make sure that your badge is clearly visible at all times during the Congress. If you lose your badge then please report it immediately to the Registration Desk in the Windsor & Eton Foyer, where you will be issued with a replacement.

Please remember to bring your badge with you for each day that you attend – this will help us reduce the need to

reprint any badges. You are also kindly asked to recycle your badge and the badge holder at the end of the Congress.

Registration desk

The registration desk is located in the Windsor & Eton Foyer outside of the main plenary room, downstairs from the hotel main reception. Registration for members will open at 08.00 on Saturday 29 March 2014. Registration for all other stakeholders will open at 16.00 on Saturday 29 March 2014.

If you have any queries during the Congress, please visit the registration desk, where staff from IAPO and Novus Event Management will be at hand to assist you.

Annual membership fees

It is possible for you to pay your organization's membership fee at the registration desk between 11.30–17.30 on Saturday 29 March.

Membership fees can be paid in cash, cheque or by credit card in sterling, euro or dollars. Please bring your organization's account number as stated on your membership fee invoice.

Emergencies

In the event of an emergency, please contact a member of staff from Novus or IAPO, or a member of the hotel staff who are located at the front desk in the main foyer of the hotel. Alternatively, dial 999 or raise the nearest fire alarm should the need arise.

Networking opportunities during the Congress

Breakfast Briefing

Saturday 29 March – 08.00

A breakfast briefing for IAPO Members will take place at 08.00 in the Park & Ascot Suite on Saturday 29 March 2014. The briefing will offer participants an introduction to the 6th Global Patients Congress and an opportunity to identify how to get the most from the event. The briefing will take the form of roundtable group discussions to explore the opportunities for delegates to engage. Experienced IAPO members will offer guidance in each discussion group. This facilitated session will offer practical advice, objectives and the chance to meet fellow IAPO members. A continental breakfast will be provided.

Welcome Reception

Saturday 29 March – 18.30

All delegates are invited to attend the Welcome Reception on Saturday 29 March, which will be held in the Exhibition Area in the Windsor & Eton Foyer. This will give you the chance to meet with others in a relaxed setting. Refreshments, including wine and soft drinks, will be served as well as canapés.

Thank You Dinner

Saturday 29 March – 19.45

This dinner is by invitation only and is to thank our sponsors, supporting organizations and others who have helped to make the Congress happen. All invitees must meet in the hotel reception area no later than 19.45 to meet the transport to the Royal Berkshire Hotel.

Pre-Dinner Satellite Drinks Reception

Sunday 30 March – 19.00

A satellite drinks reception will be held in the Exhibition Area in the Windsor & Eton Foyer before the Congress Dinner. This session is sponsored by Medtronic. All delegates are invited. Find out more on p18.

Congress Dinner

Sunday 30 March – 20.00

We would like to invite you to attend the Congress Dinner on Sunday 30 March as IAPO's guest. This will be hosted in the Windsor & Eton Suite. A regular feature at the IAPO Congress is the much anticipated IAPO quiz, which is held during the Congress Dinner. Come prepared to work with those seated at your table in a quiz which will test your knowledge of IAPO, global health and much more!

Seating at the dinner is not allocated, so please feel free to select your own seat. The dress code for this event is smart/casual and we welcome national dress.

Exhibition

All days throughout the Congress

The exhibition is an integral part of the Congress and the support of all the stakeholders at the event is greatly appreciated; please take your time to visit the stands which are located in the Windsor & Eton Foyer, directly outside the main room (see p34 for layout plan).

Lunch

All days throughout the Congress – times vary, please refer to the programme

Lunch will be served in The Hyperion Restaurant, the main restaurant of the hotel, located on the ground floor of the hotel next to the reception. Any dietary requirements will have been catered for, but please do let the serving staff or IAPO or Novus staff know if you have any specific requests.

Internet and Web Café

Available throughout the Congress

There is free Wi-Fi access for all delegates using smartphones or tablets. Internet access will be via 'the cloud', which is complimentary throughout the hotel. Delegates will be required to register when they use it for the first time but thereafter it will connect automatically.

There is also a web café located in the Berkshire Lounge outside of the Park & Ascot Suite for all delegates to make use of.

Post-event Information

Certificates of Attendance

Certificates will be sent out to delegates by email after the Congress. For any queries please speak to a member of staff at the Registration Desk.

Evaluation

An email will be sent to you with a direct link to an online conference evaluation. All your comments are greatly valued and feedback plays an important part of conference planning for future years. A paper evaluation and evaluation cards will also be available at the event.

Shuttle service to Heathrow on Monday 31 March

All delegates that have booked the shuttle service should have received an email informing them of their departure times. If you have not received this information but believe you have booked the shuttle return service, please inform a member of the Novus staff immediately at the Congress registration desk. You must be present in the reception of the Berystede Hotel at the time given. Any latecomers may lose their shuttle place, although every effort will be made to rearrange the time.



Programme at a Glance

Other Information

Accessibility

The Berystede Hotel is fully accessible by wheelchair to all public areas by ramp or lift; all of the Congress rooms are on one level, which can be accessed either by stairs or by lift from the main hotel reception. Access to the Berkshire Suite (the location for the streamed sessions in the Wentworth or Park & Ascot Suites, the web café and the quiet room for prayer and meditation) is through the doors at the end of the exhibition, where ramps have been provided to account for a few small steps.

Hearing loop

There is a fixed and a portable induction loop facility to cover all of the Congress meeting rooms. Each will be on a different frequency to each other and the hotel has provided signage in each room advising to which setting guests should turn their hearing aids.

Dress code

The dress code for the Congress is smart-casual. The dress code for the Congress Gala Dinner is also smart-casual, however national or evening dress would be welcomed.

Additional Information on Meeting Rooms and Networking Opportunities

IAPO Members Area

Located in the exhibition hall, the IAPO Members Area will showcase the work of IAPO and its members. IAPO staff will be on hand here to answer any questions you may have during breaks in the Congress programme.

Exhibition

The exhibition is an important and integral part of the Congress, featuring information and materials from a range of IAPO members and partners. The exhibition is located in the Windsor & Eton Foyer, next to Registration. It will officially open at 09.00 on Saturday and remains open until 11.00 on Monday.

Web Café

Located in the Berkshire Lounge, the web café offers an informal breakout space for delegates along with four computers with internet access.

Quiet Room for Prayer and Meditation

Located in Syndicate Room 4, close to the washrooms and opposite the Park & Ascot Suite, a quiet room has been provided for Congress delegates who need to pray or have quiet time for reflection and meditation throughout the event.

Concierge

Should you have any queries regarding the hotel and its facilities, the Berystede has a concierge desk in the main lobby that can advise you on all nearby tourist attractions and local information. The service is available 24 hours a day with a Concierge at hand to answer any queries you may have.

Environmental policy

IAPO and Novus have endeavoured to use recycled, recyclable and/or sustainable materials. Delegate bags have been responsibly sourced, with a postcard in each one that tells the story behind the cotton production.

Time zone and clock changes

The time zone in London is GMT (Greenwich Mean Time).

PLEASE NOTE: On Sunday 30 March at 00.00, the clocks will go forward one hour to 01.00. Please make sure you change your watch and alarm clock accordingly to make sure that you don't arrive late to the Congress on the Sunday morning.

miituu

During Congress breaks you will have the opportunity to record your experiences of the Congress using our feedback app, 'miituu'. You will find the miituu stand in the exhibition hall.

Media and Communications

An IAPO Congress media pack is available online to support your media activities on the 6th Global Patients Congress. We encourage you to send relevant information to your media contacts. The media pack can be downloaded from the Congress website at: www.globalpatientscongress.org

Social Media at the Congress

Throughout the Congress IAPO will be using Facebook and Twitter to highlight important messages and share live updates with our social media followers worldwide. Follow us and share your Congress experiences at:



www.facebook.com/internationalallianceofpatientsorganizations



www.twitter.com/IAPOtweets (Please use the hashtag #GPC2014)

Saturday 29 March • IAPO MEMBER ONLY DAY		
08.00	Registration and BREAKFAST BRIEFING	Park & Ascot
09.00	AGM registration and refreshments	Windsor & Eton Foyer
09.30	IAPO Annual General Meeting	Windsor & Eton Suite
11.00	Refreshment break	Windsor & Eton Foyer
11.30	PLENARY SESSION: Achieving access to healthcare	Windsor & Eton Suite
13.00	Lunch	Hyperion Restaurant
14.00	REGIONAL WORKSHOPS: Patient involvement in access to healthcare	Rooms listed on p14
14.45	Feedback from regional workshops	Windsor & Eton Suite
15.45	Refreshment break	Windsor & Eton Foyer
16.15	WORLD CAFÉ: Principles of universal health coverage (UHC) from a patient's perspective	Windsor & Eton Suite
17.15	Round up and conclusions	
17.30	Close of the day	
18.30	Welcome reception	Windsor & Eton Foyer
20.00	Thank you dinner by invitation only	Royal Berkshire Hotel

Sunday 30 March • MULTI-STAKEHOLDER DAY		
08.30	Registration and refreshments	Windsor & Eton Foyer
09.30	PLENARY SESSION: Better access, better health	Windsor & Eton Suite
10.30	Refreshment break	Windsor & Eton Foyer
11.00	STREAMED SESSIONS: E1 (EQUITY), Q1 (QUALITY) and F1 (FINANCING)	Windsor & Eton Suite Park & Ascot Wentworth
12.30	Lunch	Hyperion Restaurant
13.30	STREAMED SESSIONS: E2 (EQUITY), Q2 (QUALITY) and F2 (FINANCING)	Windsor & Eton Suite Park & Ascot Wentworth
15.00	Refreshment break	Windsor & Eton Foyer
15.30	PLENARY SESSION: Breaking barriers to access	Windsor & Eton Suite
17.30	Close of the day	
19.00	Satellite drinks reception followed by Congress gala dinner	Windsor & Eton Suite

Monday 31 March • MULTI-STAKEHOLDER DAY		
08.00	Registration and refreshments	Windsor & Eton Foyer
09.00	STREAMED SESSIONS: E3 (EQUITY), Q3 (QUALITY) and F3 (FINANCING)	Windsor & Eton Suite Park & Ascot Wentworth
10.30	Refreshment break	Windsor & Eton Foyer
11.00	PLENARY SESSION: Engaging patients to achieve universal health coverage	Windsor & Eton Suite
13.00	Lunch and close of Congress	Hyperion Restaurant



Programme: Saturday 29 March

IAPO MEMBER ONLY DAY		
08.00	Registration and BREAKFAST BRIEFING: Get the most from the Global Patients Congress Chair: Megan MacGarry, Senior Membership Officer, IAPO Speakers: Regina Namata Kamoga, IAPO Governing Board Member, and Jo Groves, CEO, IAPO	Park & Ascot
09.00	AGM registration and refreshments	Windsor & Eton Foyer
09.30	IAPO Annual General Meeting	Windsor & Eton Suite
11.00	Refreshment break	Windsor & Eton Foyer
11.30	PLENARY SESSION: Achieving access to healthcare Chair: Durhane Wong-Rieger, IAPO Immediate Past Chair Speakers: Eva Maria Ruiz de Castilla, IAPO Secretary, Matthias Wienold, European AIDS Treatment Group, and Orajitt Bumrungskulswat, Heart to Heart Foundation, Thailand	Windsor & Eton Suite
13.00	Lunch	Hyperion Restaurant
14.00	REGIONAL WORKSHOPS: Patient involvement in access to healthcare Chairs: Linda Craig and Megan MacGarry, IAPO Delegates are divided into groups based on their world regions:	
	Africa	Brockenhurst
	Asia Pacific	Park & Ascot
	Eastern Mediterranean	Lyndhurst
	Europe	Windsor & Eton Suite
	Latin America	Devonish
14.45	Feedback from regional workshops	Windsor & Eton Suite
15.45	Refreshment break	Windsor & Eton Foyer
16.15	WORLD CAFÉ: Principles of universal health coverage (UHC) from a patient's perspective Chair: Jo Groves, CEO, IAPO	Windsor & Eton Suite
17.15	Round up and conclusions	
17.30	Close of the day	
18.30	Welcome reception (All delegates welcome)	Windsor & Eton Foyer
20.00	Thank you dinner by invitation only (Meet at 19.45 in Macdonald Berystede Hotel's reception)	Royal Berkshire Hotel

BREAKFAST BRIEFING: Get the most from the Global Patients Congress
 08.00 • Park & Ascot

Chair: Megan MacGarry, Senior Membership Officer, IAPO
Speakers: Regina Namata Kamoga, IAPO Governing Board Member, and Jo Groves, CEO, IAPO

Aims of session: This breakfast briefing will welcome all first-time delegates, provide an introduction to the Global Patients Congress and an opportunity to identify how members can get the most from the and what they hope to contribute throughout the proceedings. Experienced IAPO members who have previously attended the Congress will be present to offer guidance and practical advice, and the session aims to provide all a chance for introductions to fellow IAPO members. A light breakfast will be provided during this session.

PLENARY SESSION: Achieving access to healthcare
 11.30 • Windsor & Eton Suite

Chair: Durhane Wong-Rieger, IAPO Immediate Past Chair
Speakers: Eva Maria Ruiz de Castilla, IAPO Secretary, Matthias Wienold, European AIDS Treatment Group, and Orajitt Bumrungskulswat, Heart to Heart Foundation, Thailand

Aims of session: The plenary will highlight and investigate important issues around access in healthcare and will explore the contextual issues and experience of three IAPO members from different regional perspectives. The session aims to initiate discussion on the principles necessary for universal health coverage from a patient perspective. It will also explore what tools and strategies have assisted members in addressing concerns or achieving successes in terms of access to healthcare.

REGIONAL WORKSHOPS: Patient involvement in access to healthcare
 14.00 • Rooms listed in table on p14

Chairs: Linda Craig and Megan MacGarry, IAPO

Aims of session: This session aims to facilitate a discussion with participants on the issues that affect access to healthcare. Delegates will be divided into groups, based on their world regions, where they will discuss what the key issues are in their regions relating to access to healthcare, such as the barriers to access and progress towards achieving universal health coverage. Each group will explore what the principles are for universal health coverage in their region and discuss what the role of the patient is in improving access to healthcare.

WORLD CAFÉ: Principles of universal health coverage (UHC) from a patient's perspective
 16.15 • Windsor & Eton Suite

Chair: Jo Groves, CEO, IAPO

Aims of session: In this session, participants will work towards developing a draft set of global patient-centred principles for universal health coverage. The principles will draw on the issues discussed in the previous session, moving from a regional perspective towards a global perspective. The principles will be drafted during the session and then finalised after the Congress. The session will use an interactive technique called 'World Café'.





Programme: Sunday 30 March

MULTI-STAKEHOLDER DAY			
PLEASE NOTE: On Sunday 30 March at 00.00, the clocks will go forward one hour to 01.00			
08.30	Registration and refreshments		Windsor & Eton Foyer
09.30	PLENARY SESSION: Better access, better health Welcome remarks: Kin-ping Tsang, IAPO Chair Chair: Jo Groves, CEO, IAPO Keynote speaker: Dame Sally Davies, Chief Medical Officer, UK Government		Windsor & Eton Suite
10.30	Refreshment break		Windsor & Eton Foyer
11.00	STREAMED SESSIONS:		E STREAM: Windsor & Eton Suite
	E1: EQUITY Ensuring access for all	Q1: QUALITY Challenges in achieving quality healthcare	F1: FINANCING Healthcare financing in the 21st century
			Q STREAM: Park & Ascot F STREAM: Wentworth
12.30	Lunch		Hyperion Restaurant
13.30	STREAMED SESSIONS:		E STREAM: Windsor & Eton Suite
	E2: EQUITY Patient-led initiatives for patient-centred healthcare	Q2: QUALITY Patient safety: The impact of patients in improving quality of care	F2: FINANCING Access to healthcare – who decides?
			Q STREAM: Park & Ascot F STREAM: Wentworth
15.00	Refreshment break		Windsor & Eton Foyer
15.30	PLENARY SESSION: Breaking barriers to access Chair: Marc Boutin, IAPO Treasurer Discussants: Dr Otmar Kloiber, World Medical Association (WMA), Dr Hernan Montenegro, World Health Organization, Stephen Murby Wright, Consumers Health Forum of Australia, and Dr Robert Sebbag, Sanofi		Windsor & Eton Suite
17.30	Close of the day		
19.00	Satellite drinks reception sponsored by Medtronic (all delegates invited) followed by Congress gala dinner		Windsor & Eton Suite

PLENARY SESSION: Better access, better health 09.30 • Windsor & Eton Suite

Welcome remarks: Kin-ping Tsang, IAPO Chair

Chair: Jo Groves, CEO, IAPO

Keynote speaker: Dame Sally Davies, Chief Medical Officer, UK Government

Aims of session: This session will introduce the theme of the conference: 'Better access, better health: A patient-centred approach to universal health coverage'. It will begin with an overview of the key outcomes of Members' Day and a brief description of the important principles of universal health coverage from a global patient perspective. The keynote speaker will present a top level view of the issues of access to healthcare and the role of patient engagement at a national and global level in achieving patient-centred healthcare. Delegates will have an opportunity to discuss how the principles of universal health coverage are relevant to them.

STREAMED SESSION (EQUITY): E1: Ensuring access for all 11.00 • Windsor & Eton Suite

Chair: Jonathan Tritter, Aston University, UK

Speakers: Estela Chardon, Concebir, Argentina, and Regina Namata Kamoga, IAPO Governing Board Member

Aims of session: This session will explore how healthcare systems can meet the challenge of ensuring equitable access to healthcare. The session will explore what is meant by equity, for example, equity in outcomes as well as access to healthcare services. Participants will discuss some of the barriers that populations face in accessing healthcare, such as geographical location, age, socio-economic status etc. The session will finish with a facilitated discussion on the role patients, healthcare professionals and other stakeholders in supporting healthcare systems to provide access to health for all.

STREAMED SESSION (QUALITY): Q1: Challenges in achieving quality healthcare 11.00 • Park & Ascot

Chair: Sophie Staniszewska, University of Warwick, UK

Speakers: Stephanie Miller, Health Consumers Alliance of South Australia, and Obatunde Oladapo, PLAN Health Advocacy and Development Foundation, Nigeria

Aims of session: Maintaining and improving quality of care is a key challenge facing healthcare systems wishing to expand universal health coverage. But what do we mean by quality in healthcare? How do we define it, and are definitions universal or do they vary according to different healthcare settings? This session will explore what quality of care means from the patient perspective and what the challenges are in ensuring that populations access appropriate information and treatments.

STREAMED SESSION (FINANCING): F1: Healthcare financing in the 21st century 11.00 • Wentworth

Chair: Marc Boutin, IAPO Treasurer

Speaker: Professor David Taylor, University College London (UCL), UK

Aims of session: Health systems financing is fundamental to the ability of health systems to maintain and improve healthcare. Therefore, considering the role of healthcare financing and who finances healthcare is essential in any discussion on universal health coverage. However, the economic crisis has impacted on the ability of health systems to expand universal health coverage. This session will examine different systems and the challenges in financing health systems and look at solutions to access to healthcare and how patient-centred solutions can improve access to healthcare globally.

STREAMED SESSION (EQUITY): E2: Patient-led initiatives for patient-centred healthcare 13.30 • Windsor & Eton Suite

Chair: Robert Johnstone, IAPO Governing Board Member

Speakers: Lynne van Poelgeest Pomfret, World Federation of Incontinent Patients (WFIP), Regina Namata Kamoga, IAPO Governing Board Member, and Johan Vos, Alzheimer's Disease International (ADI)

Aims of session: This session will share examples of patient-led initiatives that have promoted equity and patient-centred healthcare. A panel of presenters will share case studies from around the globe of patient-led initiatives that have led to improved access to healthcare and have contributed to the expansion of patient-centred universal health coverage. Participants will discuss what lessons can be learnt from cases studies and how they can contribute to the evidence-base of the value of patient care.





Programme: Monday 31 March

STREAMED SESSION (QUALITY):

Q2: Patient safety: The impact of patients in improving quality of care

13.30 • Park & Ascot

Chair: Nittita Prasopa-Plaizier, Patients for Patient Safety (PFPS) Programme, World Health Organization

Speakers: Peter Walsh, Action Against Medical Accidents (AVMA), Margaret Murphy, External Lead Advisor, WHO Patients for Patient Safety (PFPS) Programme, and Hussain Jafri and Jolanta Bilińska, IAPO Governing Board Members and Patients for Patient Safety Champions

Aims of session: This session will give an overview of how WHO engage patients, communities and non-governmental organizations in improving patient safety and quality of care. The session will illustrate the role of patients in improving patient safety and quality of care globally through the World Health Organization's Patients for Patient Safety Programme.

The panel will share their experiences and their work in advocating and driving efforts to improve patient safety and quality of care in different settings. This session will contribute to the overall theme of the Congress by making the case for patient involvement in healthcare and demonstrating the overall value of involving patients in policies and strategies to implement and expand universal health coverage.

STREAMED SESSION (FINANCING):

F2: Access to healthcare – who decides?

13.30 • Wentworth

Chairs/Speakers: Kin-ping Tsang, IAPO Chair, Karen Facey, University of Glasgow, UK, and Sophie Staniszewska, University of Warwick, UK

Aims of session: This session will explore who makes decisions about the healthcare we receive and the role of patients in priority setting and decision-making regarding access to treatments through processes such as health technology assessment (HTA). It will explore the status of HTA around the world, the role of patient based evidence and patient involvement in HTA and patient-centred principles for HTA.

PLENARY SESSION: Breaking barriers to access

15.30 • Windsor & Eton Suite

Chair: Marc Boutin, IAPO Treasurer

Discussants: Dr Otmar Kloiber, World Medical Association (WMA), Dr Hernan Montenegro, World Health Organization, Stephen Murby Wright, Consumers Health Forum of Australia, and Dr Robert Sebbag, Sanofi

Aims of session: This session will explore issues of what the barriers to access and healthcare are, and how to overcome them. This plenary will include a diverse panel of speakers from a variety of sectors including patients' organizations, industry partners and the World Health Organization (WHO) and include input and questions from the audience.

Pre-Dinner Satellite Drinks Reception sponsored by Medtronic

19.00 • Exhibition Area, Windsor & Eton Foyer

Engaging patients to contribute to society and share their voice on improving access to care is critical, particularly in responding to the global burden of non-communicable diseases (NCDs). Medtronic Philanthropy is pleased to host a reception for all participants, focused on strengthening health systems by advancing policies and empowering patients. Arthur Ammann, 2013 Bakken Invitation honoree, will share his story of how medical technology has empowered him to give back in communities around the world. Katie Dain from NCD Alliance will share how patient organizations can engage on key policy issues focusing on improving access on NCDs worldwide. Please be sure to join us for this dialogue and networking opportunity.

MULTI-STAKEHOLDER DAY		
08.00	Registration and refreshments	Windsor & Eton Foyer
09.00	STREAMED SESSIONS:	
	E3: EQUITY Patient empowerment: A vision for the future	Q3: QUALITY Measuring quality through patient-centred indicators
	F3: FINANCING Universal health coverage: A patient- centred vision	
		E STREAM: Windsor & Eton Suite
		Q STREAM: Park & Ascot
		F STREAM: Wentworth
10.30	Refreshment break	Windsor & Eton Foyer
11.00	PLENARY SESSION: Engaging patients to achieve universal health coverage	
	Chair: Jo Groves, CEO, IAPO Speakers: Marie-Paule Kieny, Assistant Director-General, Health Systems and Innovation, World Health Organization (WHO), and Sir Michael Hirst, Global President, International Diabetes Federation (IDF)	
		Windsor & Eton Suite
13.00	Lunch and close of Congress	Hyperion Restaurant

STREAMED SESSION (EQUITY):

E3: Patient empowerment: A vision for the future

09.00 • Windsor & Eton Suite

Chair: Rebecca Johnson, Partnerships Manager, IAPO

Speakers: Kaisa Immonen-Charalambous, European Patients Forum (EPF), and Leigh Manasco, LIVESTRONG, USA

Aims of session: This session will explore the next steps in ensuring patients are actively involved in healthcare decision-making. Patients are expected to play a greater role in their care and manage their conditions effectively. Patients are also asking for greater control as the experts in how their conditions impact on their daily lives. The session will explore the principles of patient empowerment and participants will discuss what tools and actions are needed to facilitate greater patient empowerment.

STREAMED SESSION (QUALITY):

Q3: Measuring quality through patient-centred indicators

09.00 • Park & Ascot

Chair: Jonathan Tritter, Aston University, UK

Speakers: Kathy Kovacs Burns, Best Medicines Coalition, Canada, and Catriona Menzies, Adam Czech Republic

Aims of session: This session will examine how quality of healthcare can be measured in healthcare systems from a patient perspective. The session will draw on the lessons learnt from IAPO's review of patient-centred indicators. It will use the principles developed in the first session in this stream, before moving on to discuss what success looks like. The session will act as working group to discuss what indicators can be developed to measure quality in healthcare. These indicators will have been potentially pre-drafted prior to the session, to be adapted and developed through the course of the session.





Governing Board and Staff

STREAMED SESSION (FINANCING):

F3: Universal health coverage: A patient-centred vision

09.00 • Wentworth

Chair: Rachel Seal-Jones, Senior Policy Officer, IAPO

Speakers: Orajitt Bumrungruskulswat, Heart to Heart Foundation, Thailand, and Jon Pender of GSK, representing IFPMA

Aims of session: This session will explore financing mechanisms which can enable patient-centred universal health coverage. This session will explore current models of universal health coverage using examples from both the developed world and the developing world, and from well-established health systems to health systems in transit. The session will explore how these models can be adapted globally to different contexts.

PLENARY SESSION: Engaging patients to achieve universal health coverage

11.00 • Windsor & Eton Suite

Chair: Jo Groves, CEO, IAPO

Speakers: Marie-Paule Kieny, Assistant Director-General, Health Systems and Innovation, World Health Organization (WHO), and Sir Michael Hirst, Global President, International Diabetes Federation (IDF)

Aims of session: The aim of this session is to consider the global drive towards universal health coverage and how patients and patients' organizations can contribute in partnership with other stakeholders to defining and achieving patient-centred universal health coverage.

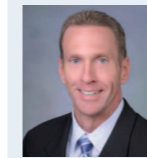
Governing Board



Kin-ping Tsang
Hong Kong, China
IAPO Chair
Chairman, Hong Kong Alliance of Patients' Organizations



Jolanta Bilińska
Poland
IAPO Chair-Elect
President, Patients Safety Foundation



Marc Boutin
United States of America
IAPO Treasurer
Executive Vice President and Chief Operating Officer, National Health Council



Eva Maria Ruiz de Castilla
Peru
IAPO Secretary
Chairperson, Esperantra



Durhane Wong-Rieger
Canada
IAPO Immediate Past Chair • Chair, Consumer Advocare Network • President, Canadian Organization for Rare Disorders



Carol Bennett
Australia
Representative, Consumers Health Forum of Australia



Hussain Jafri
Pakistan
Secretary General, Alzheimer's Pakistan



Robert Johnstone
United Kingdom
Board Member, National Voices

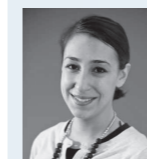


Regina Namata Kamoga
Uganda
Country Manager, Community Health and Information Network (CHAIN)

Staff



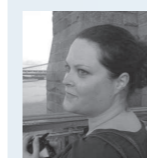
Linda Craig
Operations Director
linda@patientsorganizations.org



Yasemin Dil
Research and Policy Officer
yasemin@patientsorganizations.org



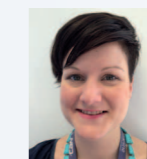
Joanna Groves
Chief Executive Officer
jo@patientsorganizations.org



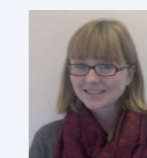
Lizette Jensen
Administrator
lizette@patientsorganizations.org



Rebecca Johnson
Partnerships Manager
rebecca@patientsorganizations.org



Megan MacGarry
Senior Membership Officer
megan@patientsorganizations.org



Rachel Seal-Jones
Senior Policy Officer
rachel@patientsorganizations.org

Governing Board Biographies



Kin-ping Tsang
IAPO Chair

Kin-ping Tsang has been on IAPO's Governing Board since 2008 and served as Chair since 2013. He founded Retina Hong Kong (RHK), a patients' self-help organization, with fellow partners in March 1995 and has been serving as President of RHK ever since.

In 2003, KP was elected as a member of the Executive Committee of the Hong Kong Alliance of Patients' Organizations in Hong Kong and, in 2005, he was appointed as Secretary. His major tasks were helping the Alliance to consolidate its internal management and develop external networks. He was elected to Chairman of APMHO in 2009 and substantially amended its constitution by setting out the core mission as 'Advocate for patient-centred healthcare and promote patient engagement'.

He is the Vice President of the Hong Kong Guide Dogs Association, and an Honorary Fellow of the Hong Kong Academy of Pharmacy. Mr Tsang has been serving on a number of committees and working groups in various bureaus and departments of the Hong Kong SAR Government. KP has been elected to the Management Committee of Retina International from 2000 to 2006, and was re-elected to the board in 2012 again. He has been serving on the Board of Age-related Macular Degeneration (AMD) Alliance International since 2006. KP is a retired business executive who is affected by Retinitis Pigmentosa, which causes severe visual impairment.



Jolanta Bilińska
IAPO Chair-Elect

Jolanta has been on IAPO's Governing Board since 2009, is currently the Chair-Elect since 2013 and served as Secretary from 2011–13. She has an MA in Clinical Psychology and is the Head of the International Cooperation Department, National Health Fund, Lodz.

Jolanta used to diagnose hospitalised children and teenagers with personal disorders. In the early 90s she started working for the regional newspaper, Dziennik Łódzki. She published almost 2,000 articles concerning medical issues and politics. Jolanta's main focus was mainly on matters relating to patients' rights and the way they are observed in the healthcare system. She also raised patients' awareness of the healthcare system and is a public health expert.

Since 2004 Jolanta has performed the function of Coordinator concerning the European Union in the National Health Fund in Łódź. Since 2005 she has been a WHO Patients for Patient Safety Champion. In 2006 she established the Patient Safety Foundation. Its main aim is to promote safety measures in health services as well as to involve patients in the process of treatment. The foundation cooperates with the Ministry of Health, WHO officers and other non-governmental organizations (NGOs) working with patients' matters.



Marc Boutin
IAPO Treasurer

Marc has been on IAPO's Governing Board and served as Treasurer since 2012. He is the executive vice president and chief operating officer of the National Health Council (NHC), an organization that brings together all segments of the healthcare community to provide a united voice for the more than 133 million people with chronic diseases and disabilities and their family caregivers.

In addition to overseeing financial management and operations at the NHC, Marc builds consensus among member patient advocacy organizations enabling them to speak with one voice on systemic health research and healthcare policy initiatives. This united effort results in legislation and regulations that address the collective needs of patients and their family caregivers. In addition, he provides guidance to patients' organizations on various association issues, including corporate structure, government relations, fundraising, and outreach. Marc is a regular spokesperson before the media, US Congress, and policy makers on major issues of interest to the patient community.

Marc has been actively involved in health advocacy, policy, and both federal and state legislation throughout his career. Aside from being a member of IAPO's Governing Board, he is also on the Community Health Charities Board of Directors, and has also served on Institute of Medicine committees, National Institute of Health panels, and the Agency for Healthcare Research and Quality's stakeholder group.



Dr Eva Maria Ruiz de Castilla
IAPO Secretary

Eva Maria has been on IAPO's Governing Board since 2010 and served as Secretary since 2013.

She is a co-founder and since 2006 Executive Director of ESPERANTRA, a not-for-profit cancer and chronic disease patient advocacy organization in Lima, Peru. Her work at ESPERANTRA is to improve the quality of life of patients with chronic conditions, to promote health, and to advance the recognition of the rights of patients to achieve access to timely diagnosis, treatment, and follow-up care. She has been instrumental in a number of national initiatives focused on cancer, including the government's Plan Esperanza launched in 2012 to provide basic cancer care coverage for the poorest and most vulnerable Peruvians.

In addition to her work with ESPERANTRA, Eva Maria consults part-time for various Peruvian ministries, including Health, Social Development, Housing, Women, and Water-Sanitation to help design and coordinate the country's public sector social assistance programmes. From 2011 to 2012, Eva Maria was Director General of the Peruvian Ministry of Health's (MINSA) International Coordination office and before that served as MINSA's Director General of Health Prevention and Promotion. She has in-depth experience working with donor country agencies and multilateral organizations such as the World Bank.

As a Board Member of IAPO Eva Maria has been a global leader in patient-based organizational capacity building and has led various workshops on patient empowerment and networking. Her experience and involvement with building the capacity of civil society organizations focused on cancer in Peru earned her the American Cancer Society's "Excelencia Latina 2009" Award. In 2011, Eva Maria was named a Global Cancer Ambassador by the American Cancer Society, and was invited by WHO to participate as a civil society representative during the UN High-Level Meeting on non-communicable diseases.



Dr Durhane Wong-Rieger
IAPO Immediate Past Chair

Durhane has been on IAPO's Governing Board since 2007; she served as Chair from 2011–13 and has been Immediate Past Chair since 2013. She is on the Governing Board of DIA International and Co Chair of the Health Technology Assessment International Patient/Citizen Involvement Interest Group. In Canada, she is the founder and head of the Consumer Advocare Network, a national network to provide a common voice for patients' organizations. She is also president of the Canadian Organization for Rare Disorders, and President and CEO of the Institute for Optimizing Health Outcomes. She is a member of the Advisory Board for the Canadian Institute of Health Research Institute of Genetics.

Durhane has conducted training, workshops and evaluation for patient groups in Canada and internationally on all aspects of patient engagement and advocacy. She has served on numerous health policy advisory committees and panels, including Project Coordinator for the Policy Dialogues for the Commission on the Future of Healthcare in Canada and consultant to the Ontario Premier's Advisory Board on Organ Donation.

Durhane's current research and publications include chronic disease self-management and health coaching, measuring quality of life, patient engagement in health technology assessment, and rare diseases/personalised medicines.

From 1984 to 1999, Durhane was Professor of Psychology at the University of Windsor in Ontario, Canada. Durhane has a BA in Psychology from Barnard College in New York City and an MA and PhD in Social Psychology from McGill University in Montreal. She is author of two books and many articles and a frequent lecturer and workshop leader. Durhane is married with two children, each with a rare health condition.



Carol Bennett
IAPO Governing Board Member

Carol has been on IAPO's Governing Board since 2012. She is the Chief Executive Officer of the Hunter Medicare Local – one of the largest not-for-profit primary healthcare organizations in Australia that aims to improve the health of local communities based on a model of strong consumer engagement.

Prior to this role, Carol was CEO of the Consumers Health Forum of Australia (CHF), the foremost national organization for health consumers in Australia. She led CHF's work to ensure a strong consumer voice and consumer participation in health reform through advocacy, policy development and consumer research. Carol is still the IAPO representative for CHF.

Carol has worked at the executive level in health organizations for more than 15 years, including as CEO of key national and state health bodies, and in major consultancy roles with many organizations, including beyondblue, the national depression initiative. She is a member of key national advisory bodies including Council Member of the National Health and Medical Research Council (Australia's leading expert body promoting the development and maintenance of public and individual health standards). Carol works collaboratively with those at the most senior levels of government, as well as representatives from significant health industry, professional and consumer groups and is committed to the role of non-government organizations as drivers of improved outcomes for their communities.



Hussain Jafri
IAPO Governing Board Member

Hussain has been on IAPO's Governing Board since 2005 and served as Chair from 2009–2011.

Hussain is the Secretary General and IAPO Representative of the Council for Alzheimer's Pakistan, the national association of Alzheimer's Disease and related dementias. Hussain founded Alzheimer's Pakistan in 1999 as a result of his experiences as a caregiver for his grandfather with Alzheimer's Disease.

Hussain runs his own tourism company and also works as a consultant in the medical field. He is working as Research Coordinator for University of Leeds, UK and Cambridge University, UK in a collaborative research programme on gene location between Pakistan and the UK, funded by a Wellcome Trust Grant. He is a keen researcher and has several international publications to his credit.

He also works closely with the government of Pakistan on various health issues. Hussain has run projects such as Safe Motherhood Initiative and Punjab Thalassaemia Prevention Program, which is one of the largest Thalassaemia prevention programmes in the world. He is a WHO Patients for Patient Safety Champion (PFPS) and a PFPS representative of Eastern Mediterranean Region (EMRO).

Hussain has notable experience of working as a volunteer in the social sector and has had an opportunity of working with government, national and international non-profit organizations. Besides his commitment to IAPO, he is an active Board Member of numerous other organizations.



Robert Johnstone IAPO Governing Board Member

Robert has been on IAPO's Governing Board since 2010. He is a trustee and IAPO representative from National Voices in the UK (a coalition representing more than 150 health and social care organizations). Having had chronic rheumatoid arthritis for 58 years, he has not had a conventional career but has served on many charities representing disabled people and those with health challenges. For many years he was active in a network called People with Arthritis and Rheumatism in Europe (PARE) where he was involved in lobbying the European Parliament and senior policy makers to raise the profile of musculoskeletal conditions.

At a global level he served as President of Arthritis and Rheumatism International (ARI) and worked in the Bone and Joint Decades as a patient advocate. Within the UK he helped the NHS develop Shared Decision Making materials for patients to empower them in relationships with health professionals and on the development of Personal Health Budgets to give people with chronic conditions financial autonomy to purchase healthcare.



Regina Namata Kamoga IAPO Governing Board Member

Regina has been on IAPO's Governing Board since 2005. She is the Country Manager and

IAPO representative for the Community Health And Information Network (CHAIN) in Uganda, an organization that promotes the empowerment of people living with and affected by HIV/ Aids, TB, Malaria and other non-communicable diseases, and supports orphans and vulnerable children. CHAIN also promotes patient-centred healthcare and patient safety.

Regina has a wide range of experience in project management and healthcare issues and has been actively involved in activities addressing the plight of patients. She has worked on capacity building for NGOs and Community-Based Organizations (CBOs) in governance and policy issues, health literacy and access, building and strengthening networks in collaboration with other organizations at the international, national and community level to address issues of patient safety and patient-centred healthcare.

Regina has served on numerous health advisory committees, panels and boards at national and international level. She is the chairperson of the Uganda Alliance of Patients Organizations (UAPO), Board Member of Joyce Fertility Support Centre, Uganda, member of the external reference group for the impact assessment of the Access to Medicines index and the regional coordinator for the Africa regional network of patients' organizations.

She served as a steering committee member on a WHO-based tropical disease research programme (TDR) focusing on emerging diseases and is one of the authors of the WHO-TDR report on implementation research for the control of diseases of poverty, strengthening the evidence base for the access and delivery of new and improved tools, strategies and interventions. She is also a WHO Patient for Patient Safety Champion.



Joanna Groves Chief Executive Officer

As Chief Executive Officer, Joanna is responsible for managing and implementing IAPO's overall strategy. Joanna joined IAPO in March 2004 as Policy & External Affairs Director and was promoted to CEO in March 2007. She also takes a leading role in developing and communicating IAPO policy on healthcare issues, ensuring that it represents the views of IAPO's member patients' organizations, and building partnerships with other international health-related organizations.

With a science policy background and a particular interest in how health policy is formulated, Joanna supports a stronger role for patient consultation and social and ethical considerations in health policy making. She has worked in other non-profit health organizations including a policy and research capacity building role in The Wellcome Trust's Biomedical Ethics Section. Joanna holds a Master's degree with Distinction in Science and Technology Policy Studies from the Science Policy Research Unit (University of Sussex) and a BSc in Physical Sciences from University College London.



Lizette Jensen Administrator

Lizette has been with IAPO since January 2012 as Administrator and handles IAPO's finance, membership and office administration. Lizette moved to London from Denmark in 2006 to take on a role for a Danish charity where she stayed for three years. Since then she has worked in the hospitality and public sectors.



Rebecca Johnson Partnerships Manager

Rebecca joined IAPO in July 2009 and has worked in a number of roles within the team, including providing communications, project and administrative support to various projects and core activities. In January 2013 Rebecca became the Partnerships Manager, managing IAPO's sponsorship and fundraising activities, overseeing collaborations and management, supporting a number of IAPO's projects including Volunteer Management and leading on IAPO's Regional Strategy for Latin America.

Rebecca has a keen interest in international issues such as health, human rights and gender. This is reflected in her degree in International Development (BA Hons) from the University of Liverpool. As well as her role at IAPO, in order to build on her knowledge and skills, in September 2013 Rebecca began a Master's in Public Administration: International Development. Rebecca has travelled extensively, both through work and for pleasure. To support her studies for her BA, she visited Southeast Asia to research human trafficking in the region. Rebecca is also interested in Latin America and has studied Latin American Politics, History and Spanish.



Megan MacGarry Senior Membership Officer

As Senior Membership Officer, Megan is responsible for leading on IAPO's membership programme and outreach, and engages with patients' organizations worldwide. She works on capacity building for members and growing global engagement with IAPO and its core areas of work.

Before joining IAPO, Megan worked at CIVICUS: World Alliance for Citizen Participation. There she held a number of roles, including Network Coordinator of the Affinity Group of National Associations, a global network of national level civil society platforms of which CIVICUS was the Secretariat. She was also a core member of the Convening team, responsible for CIVICUS's membership and engagement, events and capacity building of the network. Previously she also held the role of Coordinator of the Every Human Has Rights campaign, a global movement seeking to raise awareness of and foster individual action on the Universal Declaration of Human Rights. Before this, she was a researcher at the Centre for Development and Enterprise (CDE), a leading policy think tank in South Africa, examining critical national and regional policy issues. She has a Master's in Development Studies from the School of Development Studies at the University of KwaZulu-Natal, South Africa, and a Bachelor of Social Science in Politics and English.

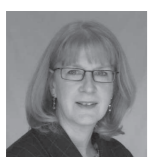


Rachel Seal-Jones Senior Policy Officer

As Senior Policy Officer, Rachel works to develop and implement IAPO's policy strategy. She has developed IAPO's policy positions on a range of areas including non-communicable diseases, access to healthcare and clinical trials. She has worked on the development of IAPO's policy programme at the Global Patients Congress. Rachel also supports the monitoring and evaluation of IAPO's strategic plan and leads IAPO's regional work in South-East Asia and the Western Pacific.

Before joining IAPO, Rachel worked in the public sector where she worked on government housing policy strategy at the Homes and Communities Agency (HCA). Prior to that she worked as a researcher for the Institute for Public Policy Research (IPPR), a leading think tank in the UK, where she undertook research on a range of policy issues such as the impact of the recession on low-income households. Rachel has also worked for a national children's charity, Barnardo's, in their policy and strategy unit where she conducted research on policy issues such as child poverty, education, housing and the laws regarding the provision of benefits to refugees and asylum seekers. Rachel has an MA in History and a BA (hons) in English and History both from the University of Leeds.

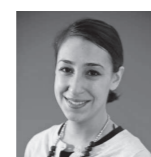
Staff Biographies



Linda Craig Operations Director

Linda Craig joined IAPO as Operations Director in September 2013, following interim senior roles at the Cystic Fibrosis Trust and Suzy Lamplugh Trust. She was also Interim Director at Vauxhall City Farm for a year. An Information scientist by background, she has an MSc and Diploma in Information Science from City University and a BA (Hons) in Modern English Studies from the University of Cardiff.

Linda started her career running information services in industrial market research organizations in the commercial sector, before moving to the voluntary sector as Director of Information Services at the Institute for the Study of Drug Dependence (now Drugscope). She spent seven years as General Secretary of Quaker Peace & Social Witness, and was then the Director of Pesticide Action Network UK; in both of these posts she worked with networks of grassroots organizations in a number of countries.



Yasemin Dil Research and Policy Officer

Yasemin joined IAPO in February 2012 as a researcher to conduct a systematic literature review for the Patient-Centred Indicators Project. She now supports IAPO's research and policy activities, as well providing project support, coordination and management for IAPO's internal and external project work. Most recently Yasemin developed an Information and Advocacy Toolkit on Biological and Biosimilar Medicines for Patients' Organizations.

Yasemin has an MSc in Control of Infectious Diseases from London School of Hygiene and Tropical Medicine and a BSc in Biomedical Science from University College London.



Speaker Biographies

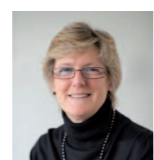


Estela Chardon
Secretary, CONCEBIR

Estela worked for many years in both the public and private sectors as an engineer until she discovered in the early 90s that she was infertile. She undertook to become pregnant with Assisted Reproduction Techniques including egg donations. Due to her experiences, Estela decided to leave her job and start a Patients' Association to support infertile couples.

Together with Isabel Rolando (CONCEBIR President), Estela founded CONCEBIR, the first infertile patients' organization in Latin America. She studied Psychology, completing her degree in 2007. She later specialised in the area of maternity health as Perinatal Psychologist and in 2010, she finished her Master's degree in Familiar Cognitive Therapy.

She is now professor of the University of Buenos Aires, working in the neonatal intensive care unit of a maternal hospital as well as the team for Childhood and Family in a private therapy clinic. She is a Board Member of Infertility Consumer Support for Infertility, the organization that connects infertile patients' associations globally. Estela is a chemical engineer graduated from Buenos Aires University and is married with two daughters.



Professor Dame Sally C Davies
Chief Medical Officer, UK Government

Professor Dame Sally Davies is the Chief Medical Officer (CMO) for England and also advises the UK Government. She holds responsibility for Research and Development, and is the Chief Scientific Adviser for the Department of Health. The CMO is the independent advisor to the Government on all medical matters, with particular responsibilities regarding Public Health. In particular, she provides professional leadership for Directors of Public Health and will lead a public health professional network for those responsible for commissioning and providing public health services.

Sally has been actively involved in NHS Research & Development (R&D) from its establishment. As Director-General she established NIHR with a budget of £1 billion. Sally led the UK delegation to the World Health Organization (WHO) Ministerial Summit in November 2004 and the WHO Forum on Health Research in November 2008. She spoke on R&D at the World Health Assembly in May 2005 and is a member of the WHO Global Advisory Committee on Health Research (ACHR). She also chaired the Expert Advisory Committee for the development of the WHO research strategy, endorsed by the World Health Assembly in May 2010. She is a member of the International Advisory Committee for A*STAR, Singapore and has advised many others on research strategy and evaluation. Sally was awarded a DBE (Dame Commander of the British Empire) in the New Year Honours 2009 for services to medicine. In September 2011 Sally was conferred as Emeritus Professor at Imperial College London.



Orajitt Bumrungkulswat
Assistant Secretary General,
Heart to Heart Foundation

Orajitt is currently Assistant Secretary General, Heart to Heart Foundation, as well as Director, Medical Rehabilitation, Thai Traditional Medical and Community Healthcare Program, National Health Security Office. The Heart to Heart Foundation was established in 2008 with the aim to bring together patients with chronic diseases requiring high-cost treatments to provide them with the ability for self-care, as well as caring for fellow patients to help provide an improved quality of life.

She has 35 years of experience in policy and plan analysis, civil society and community development, strategic planning and advocacy, local and community fund management, people and patient participation and empowerment, participatory monitoring and evaluation.

Orajitt holds a Bachelor in Economics from Chulalongkorn University and has a Master of Science in Human Settlement, Planning and Development from the Asian Institute of Technology. She also holds the Certificate in Housing Planning from the Institute for Housing Studies in the Netherlands. She lives in Bangkok, Thailand, and is married with two sons.



Dr Karen Facey
Honorary Senior Research Fellow,
Department of Health Economics and
HTA, University of Glasgow

Karen Facey is a medical statistician who has worked in the pharmaceutical industry and medicines regulation. Twelve years ago she set up the first national health technology assessment (HTA) agency in Scotland, which sought to engage patients throughout the HTA process. She is now an independent HTA consultant and a member of the Scottish Health Technologies Group that appraises non-medicinal technologies.

Karen was Chair of the Interest Group on Patient/Citizen Involvement in HTA for seven years and is now undertaking two research projects for them – developing principles for patient engagement in HTA and outlining processes to support patients' organizations to submit patient perspectives to HTA.

Karen has been guest editor on a specially-themed edition of the International Journal of Technology Assessment in Health Care about patient issues and is currently co-editing a special edition of The Patient journal about rare diseases.



Sir Michael Hirst
Global President,
International Diabetes Federation (IDF)

Michael Hirst was elected President-Elect of IDF at the World Diabetes Congress in Montreal in October 2009, and succeeded Professor Jean Claude Mbanya of Cameroon as President on 1 January 2013. He will serve as President until the conclusion of the World Diabetes Congress in Vancouver in December 2015.

Michael's interest in diabetes started over 25 years ago when his younger daughter was diagnosed with type 1 diabetes at the age of five. He was then a Member of the British Parliament and campaigned vigorously for improved care for people with diabetes. He was thereafter co-opted to the board of trustees of the British Diabetic Association, now Diabetes UK, where he served in a number of capacities before becoming the first non-medical Chair in 2001. He served as Chair until February 2006, and is now a Vice President of Diabetes UK.

He was Deputy Chair of the international steering group of UNite for Diabetes, the campaign for a UN Resolution on Diabetes, which was secured in December 2006. Currently he co-chairs the TIDES project, which seeks to improve diabetes services in emergency and disaster situations, and co-chaired the IDF meeting in London that launched the global project to secure essential diabetes medicines for children in the developing world.

Michael is a graduate in law, a qualified chartered accountant, and was a partner in KPMG until his election to Parliament. After fifteen years in front-line politics, he returned to a career in business, and is now non-executive chairman of the Pagoda Public Relations Group and the Millstream Group. He was knighted



in 1992 for political and public service in the UK, and has been chairman of the Scottish Knights since 2002. He also holds a number of voluntary appointments in charities and public bodies.



Kaisa Immonen-Charalambous
MA
Senior Policy Adviser,
European Patients Forum (EPF)

Kaisa is responsible for leading EPF's policy formulation and advocacy work at EU level, giving policy analysis and advice, liaising with the EU institutions and stakeholder organizations, and developing EPF's advocacy strategy. Her areas of responsibility include patient empowerment and improving the quality and safety of healthcare, health literacy and information to patients, clinical trials, cross-border healthcare, the EU regulatory framework on pharmaceuticals, and collaboration with the European Medicines Agency. She has previously worked in EU health policy, patient advocacy and external communications roles in the private and non-profit sectors.

EPF is a not-for-profit, independent umbrella organization of patients' organizations in the EU, currently with 62 member organizations active in public health and health advocacy. Its mission is to ensure the patients' community drives policies and programmes that affect patients' lives and to bring the changes needed to empower them to be equal citizens in the EU.



Robinah Kaitiritimba
Executive Director,
Uganda National Health Users/
Consumers' Organization (UNHCO)

Robinah Kaitiritimba is a Patient Champion for the WHO Patient Safety Programme. She holds a Master's Degree in Public Administration and Management and a Bachelor of Arts in Sociology and Political Science. She has trained in Health and Human Rights, Non-Governmental Organization management, integrating gender and health for poverty reduction and policy advocacy and leads a coalition of patients' organizations, Voices for Health Rights (VHR). She is a Fellow of the African Health Research Forum (AfHRF) and was invited as a Visiting Lecturer on health policy at the Institute of Public Health in Antwerp, Belgium.

Robinah is a member of the National Health Policy Advisory Committee (HPAC) and the National Quality Improvement Committee, as well as the National Supervision Monitoring and Research, Health Human Rights and Gender, and Sector Budget Working Groups of the Ministry of Health. She has made presentations and done research on various topics at national and international levels in the area of human rights and quality of health, focusing on healthcare consumer empowerment and participation. Her greatest contribution has been community empowerment for improving healthcare user participation and overall health outcomes for vulnerable communities and contribution to the development of the Patients' Charter for Uganda.



Dr Marie-Paule Kiény
Assistant Director-General,
Health Systems and Innovation,
World Health Organization (WHO)

Dr Marie-Paule Kiény was appointed Assistant Director-General at WHO in October 2010 and is now leading the Health Systems and Innovation cluster. Prior to this, Dr Kiény directed the WHO Initiative for Vaccine Research since its inception in 2001. Major successes under her leadership were the development and licensing of new vaccines against meningitis and measles, and against pandemic influenza in developing countries through pioneering the transfer of technology and know-how.

Before coming to WHO, Dr Kiény held top research positions in the public and private sectors of her home country, France. These positions included Assistant Scientific Director of Transgene S.A. from 1981 to 1988, and Director of Research and Head of the Hepatitis C Virus Molecular Virology Group at the Institute of Virology, Institut national de la santé et de la recherche médicale (INSERM) from 1999 to 2000.

She received her PhD in Microbiology from the University of Montpellier in 1980, where she was also awarded a University Diploma in Economics, and her Diplôme d'Habilitation à Diriger des Recherches from the University of Strasbourg in 1995.



Otmar Kloiber
Secretary General,
World Medical Association

After studying medicine at the University of Cologne, Otmar Kloiber joined the Department of Biochemistry at the University of Minnesota, Duluth in 1985. He continued as a research fellow at the Max-Planck-Institute for Neurological Research in Cologne until 1991 when he joined the German Medical Association. There he worked in various functions and finally left as Deputy Secretary General.

Since 2005 he serves as Secretary General of the World Medical Association, which is the global organization of currently 106 national medical associations. He is interested in the development of deontology under the influence of health system organization and its relation to the provision of medical care.

Otmar is a Fellow at the Center for Global Health and Medical Diplomacy, University of North Florida where he also has been Clinical Professor in Health Administration from 2009 to 2013.



Dr Katharina (Kathy) Kovacs Burns
MSc, MHSA, PhD
Board Director, Best Medicines Coalition

Kathy's academic, research and volunteer interests include public, patient and stakeholder engagement and knowledge management in patient-centred healthcare, social support

programmes/services and policy decisions. Specifically, she is interested in the barriers and enablers of programme and policy decisions which impact on service and/or coverage availability, accessibility, equity, safety and effectiveness on quality of life and other life dimensions.

As Associate Director, Health Sciences Council, and Director, Interdisciplinary Health Research Academy, University of Alberta, she coordinated interdisciplinary and inter-professional health sciences research, education and practices, including with government, community and health partners.

Nationally, she is Chair or member of several scientific committees for spinal cord injuries, neurological strategies and research funding. She engages with government ministries and agencies on health issues, including with Health Canada, Public Health Agency of Canada and the Institute of Health Economics. Internationally, she is involved with the WHO Patients for Patient Safety programme and major global studies including Diabetes Attitudes, Wishes and Needs (DAWN2). She mentors, does consultations, reviews grants, publishes in journals and books, and presents at special events, meetings and national and international conferences.



Leigh Manasco
Training and Development Manager,
Community Programs and Engagement,
LIVESTRONG Foundation

Leigh earned her Bachelor of Arts in English from Rhodes College in Memphis, Tennessee, USA in 2001. She began her career in adult education and development at Quiznos, a restaurant chain with more than 5,000 restaurants worldwide. There she created and facilitated hundreds of training sessions that focused on restaurant operations, local store marketing, and financial systems.

In 2009, Leigh moved to the non-profit sector, where she has been able to utilise her experience to help organizations and advocates build their capacity and skills in the fight against cancer. She currently directs the LIVESTRONG Foundation's training and education initiatives, focusing on training individuals and organizations on how to implement and advocate for patient-centred care.



Catriona Menzies
Member, Adam Czech Republic

Catriona Menzies was born in Edinburgh but now spends most of her time in Central Europe, where she is a teacher and translator and language editor for a number of journals. She studied Communication Studies at Queen Margaret College, Edinburgh, before moving on to do an MPhil in East European Studies at Glasgow University and then a Doctorate Degree in Politics at the University of London. Over a year ago, she became an official member of Adam Czech Republic, a patients' organization dealing with fertility

issues, thereby making official her interest in fertility issues and healthcare policy.

Adam Czech Republic provides men and women with information and advice on fertility issues. It is a member of various national and international organizations, such as Fertility Europe. It is also represented on a government commission and the assisted reproduction section of the Ethics Commission in the Czech Republic. Adam Czech Republic has also been involved in research projects relating to infertility and foster care. Adam Czech Republic has recently become more involved in ethical issues and patient-centred medicine, publishing a book entitled 'Trust-based Medicine'. It is also co-hosting a conference on research methods in České Budějovice in January 2014.



Stephanie Miller
Executive Director, Health Consumers
Alliance (HCA) of South Australia

The HCA is the peak body for health consumers in South Australia, established in 2002. As an independent alliance of health consumers and health consumer organizations, HCA works together with its members to achieve a vision of consumers at the heart of healthcare. A strong and effective voice for the promotion and protection of health consumer wellbeing and rights, HCA promotes health equity and provides systemic advocacy to inform, shape and sustain consumer-centred care.

Prior to joining HCA in April 2009, Stephanie lived in the UK for 14 years where she held senior executive roles with consumer-focused not-for-profit and public sector organizations. Stephanie has been Presiding Member of the Health and Community Services Complaints Advisory Council in South Australia since July 2010. She is also a member of the South Australian Council for Safety & Quality in Health Care and Chair of the South Australia Health's Partnering with Consumers Advisory Group.

Stephanie has a Master's Degree in Management and Social Responsibility from Bristol University and a Post Graduate Certificate in Dialogue, Deliberation and Public Engagement from Fielding Graduate University in the US.



Dr Hernan Montenegro
Health Systems Adviser,
World Health Organization (WHO)

Dr Montenegro holds a Medical Doctor degree from the University of Chile, a Specialist in Public Health degree from the University of Chile, and a Master in Public Health degree from the University of Johns Hopkins. He also has two years of postgraduate training in General Surgery at the University of Chile's Jose Joaquin Aguirre Hospital.

At the beginning of his career, he served as a clinician providing primary and emergency care services to low-income populations in Santiago, Chile. From 1988 to 1995, he was a professor of

public health at the School of Public Health of the University of Chile. From 1991 to 1995 he worked for the Chilean Ministry of Health, first as a Public Health Specialist, and later on, as the Head of the Health Sector Reform Project Coordination Unit. In 1996 he joined the World Bank where he became Senior Health Specialist for the Human Development Sector Management Unit, Latin America and Caribbean Region, in Washington, DC.

While at the World Bank, he worked in Panama, Mexico and Brazil. In 2001 he joined PAHO/WHO as Regional Advisor on Hospital and Health Services Management, and later on from 2004 to 2007 he became Chief of the Health Services Organization Unit of PAHO/WHO in Washington, DC.

Dr Montenegro's areas of expertise are health services organization, management and delivery, health systems, health sector reform, health policy, strategic planning, and project/programme formulation and evaluation.



Stephen Murby FRSA
Board Director, Consumers Health
Forum of Australia (CHF)

Born in Melbourne, Australia, Stephen has lived on the far north-west coast of Scotland since 2012. He is a Board Director of CHF, a member of the International Advisory Board of the Alliance for Safe Biologic Medicines in the US and a Life Fellow of the Royal Society of Arts (RSA) UK.

In 2006 Stephen moved into the community sector as CEO of Cystic Fibrosis Victoria (CFV) in Australia. During his six-year tenure at CFV he was also Chair of the Chronic Illness Alliance, Chair of CHF and a Board Member of the Australian Council for Healthcare Standards. Formerly, Stephen was Vice President of Swinburne University of Technology, where he worked for nine years. Before joining Swinburne he spent five years in Hong Kong and was the Foundation Head of Continuing and Community Education at the now-named Open University of Hong Kong.

Stephen has spent over 30 years in 'Greenfield' public and community sector innovation around the world. He has travelled widely in Europe, Asia and North America. He has diverse community interests, working with a number of community organizations, groups and councils. He has been a Board Member of the Sir Edward Dunlop Medical Research Foundation, Chairman of More Than Opera and a Director of the RSA in Australia and New Zealand.



Margaret Murphy
External Lead Advisor,
WHO Patients for Patient Safety

Following the death of her son as a result of medical error, Margaret Murphy has been actively involved as a patient safety advocate. The focus of her work relates to seeing adverse events as having the potential to be catalysts for change



as well as being opportunities for learning, identifying areas for improvement and preventing recurrence. She promotes this viewpoint at local, national and international levels as an invited presenter to conferences, hospital staffs and students. Her area of particular interest is education as a vehicle to achieve sustainable culture change.



Jon Pender

Vice President, Government Affairs, Global Health, GlaxoSmithKline (GSK)

Jon Pender is responsible for ensuring that GSK's approach to sustainably improving access to medicines in the developing world reaches as many people in need as possible, whilst protecting the fundamental business model which underpins the research-based pharmaceutical industry.

Jon has participated in a number of hearings, workshops, seminars, evidence sessions and other events on access to medicines and partnership issues including at the UK Parliament, European Parliament and Commission, UN, World Bank, WTO and the WHO.

Jon works with a wide range of stakeholders, including governments, NGOs, multilateral agencies, investors and the media, and represents GSK at a number of international organizations such as the WHO and WTO. He is the Board Member for the Private Sector at the Roll Back Malaria Partnership and has regularly attended the board meetings of the Global Fund to Fight AIDS TB and Malaria. He is Chair of the CBI's WTO Working Group and the IFPMA's Global Health Committee and co-Chairs the UK's Industry Government Forum on Access to Medicines (IGFAM).

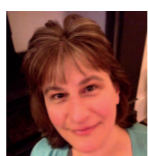


Dr Robert Sebbag

Vice President Access to Medicines, Sanofi

Dr Sebbag participates in Sanofi's access to medicines strategy development for the southern hemisphere. Prior to joining Sanofi, Dr Sebbag worked in Brussels for the European Pharmaceutical Industry Association (EFPIA) on creating a communications platform for the pharmaceutical companies operating in Europe. In his prior role, he was Senior Vice President of Communications for the vaccine company Aventis Pasteur (today known as sanofi pasteur).

In addition to his activities within the pharmaceutical industry, Dr Sebbag is also teaching public health courses within the Paris hospital system, focusing on tropical parasitic diseases. Dr Sebbag is active within the French Red Cross and has participated in numerous health missions in the Southern Hemisphere. Dr Sebbag is a Doctor in Medicine with specialty in tropical parasitic diseases and training in psychiatry.



Dr Sophie Staniszewska

Senior Research Fellow, University of Warwick

Sophie Staniszewska leads the Patient and Public Involvement and Patient Experiences Programme at the Royal College of Nurses Research Institute, Warwick Medical School, University of Warwick. She has carried out a wide range of studies, recently completing a scoping study for NICE which developed the Warwick Patient Experiences Framework that informed the NICE Patient Experiences Guidance. Sophie recently chaired the NICE Patient Experiences Guideline and Quality Standard and is a member of the National Quality Board Patient Experiences sub-group.

Sophie is also a member of the Research Excellence Framework 2014 Public Health, Health Services and Primary Care Panel. Until recently, Sophie chaired the Evidence, Knowledge and Learning Group of INVOLVE and was a member of the Main Group of INVOLVE. She is also a member of the Health Technology Assessment International Patient/Citizen Involvement Steering Group and co-chairs the Methods and Impact Group.

Sophie reviews for a range of funding bodies and international journals, is on the editorial board of a number of journals including the International Journal for Quality in Health Care, Patient Experiences Journal, and The Patient: Patient Centered Outcomes Research.



Professor Jonathan Tritter

Professor of Sociology and Public Policy, Aston University

Jonathan's main research interests relate to public participation and lay experience in policy-making and service development, particularly in relation to health and environmental policy. He is involved in a range of international and national research and development work that focuses particularly on the evidence base on the impact of patient and public involvement.

Jonathan has degrees from the University of Chicago and Oxford University. He established and led the National NHS Centre for Involvement from 2006 to 2009. He has also supported the development of Public Health England's public involvement strategy, is Chair of the Public Health England Equality Forum and is a member of Public Health England Health Equity Board. He is Editor-in-Chief of 'Health Expectations'.

His latest book, written along with Koivusalo, Ollila and Dorfman, is 'Globalisation, Markets and Healthcare Policy: Redrawing the Patient as Consumer', which was published by Routledge in August 2010.



Mary Lynne Van Poelgeest-Pomfret

President, World Federation for Incontinent Patients (WFIP)

Mary Lynne Van Poelgeest-Pomfret (Lynne) is President and founding member of WFIP, a not-for-profit federation of national incontinence patients' organizations throughout Europe and beyond, whose mission is to champion the interests and rights of people suffering from all forms of incontinence and associated pelvic floor disorders.

Lynne is also the Chairperson of the Dutch Interstitial Cystitis Patients' Association (ICP) and a Board Member of the Multinational Interstitial Cystitis Association (MICA). As such she has many dealings with the European rare diseases community (Eurordis). She is also a member of the Continence Promotion Committee of the International Continence Society. She is a Board Member of Epossi, a Brussels-based multi-stakeholder European think tank and a member of the European Forum for Good Clinical Practice's Ethics Working Group.

More recently, she has become a member of the Steering Group of the Medtech-European Patients Forum (EPF) Patients' Dialogue and is also a member of the EPF Strategic Planning Working Group. After graduating in French and Spanish and later Sociology, Lynne became a lecturer in Applied Language Studies in London. She later moved to the Netherlands where she was employed as a staff translator for Shell International Petroleum Company. She recently completed a Master's degree in French language and literature at Leiden University. Born in Liverpool, UK, to a Spanish mother, Lynne speaks four languages fluently.



Johan Vos

Deputy Executive Director, Alzheimer's Disease International (ADI)

Born in Holland, Johan lived in Venezuela and Chile as a child and later moved to New Zealand in 1985. After completing his studies in business management and marketing, he volunteered with Unicef and thus started his career in the charity sector, working into senior management positions for some of the largest and most respected health charities.

A desire to work internationally saw Johan and his family relocate to the UK in 2012 to take up a new position with ADI. He is responsible for developing new strategic partnerships, implementing new projects, leading ADI's regional development and advocacy programmes, developing capacity of international Alzheimer associations and deputising when required.

Johan is an international Certified Fundraising Executive (CFRE), was made a Fellow of the Fundraising Institute of New Zealand and is an active member of Rotary.



Dr Matthias Wienold MD, MPH
Member and Co-founder, European AIDS Treatment Group

Over the years, Matthias has studied medicine in Marburg, Glasgow and Kassel, and Public Health in Hannover. As a physician, he worked in hospital (dermatology) and private practice (general medicine). He has focused his work around patient empowerment and education, and health systems management at the Social Ministry of Lower Saxony and the German Federal Ministry of Health. After some time as an independent researcher, consultant and project director since 2009, he now works as Consulting Physician and Trained Peer Messenger to the Association of Physicians in Ambulatory Care for the State of Brandenburg in Potsdam.

Matthias began his patient community-oriented work as a volunteer and director of a local AIDS service organization in 1987. He is a co-founder of the European AIDS Treatment Group, founded in 1992. He has contributed a strong voice to the field of patient participation in clinical research in Europe. He has edited and published papers related to issues of access to care and prevention and has served as an advisor to many international organizations. He became a WHO Patient for Patient Safety Champion in 2005. He lives in Berlin, Germany, with his husband and zoo.





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Yet it's not just about finding new treatments. We look at these medical challenges in a broader context. We go beyond the medicine – ensuring people have the information, education and support to access the treatments they need and use them correctly for the best possible results. Helping people live full and happy lives inspires us. And promising new science and technology spur.

Today's medical challenges are far more complex than ever before. That's why we never limit the search for new medicines to our own four walls. We look at the world as our lab, seeking innovative ideas wherever they occur. We believe in connecting our own expertise and capabilities with those of others, seeking the most creative minds in every field. Together, we can solve problems and find transformational solutions. At Janssen, we collaborate with the world for the health of everyone in it.

www.janssen.com



Lilly, a leading innovation-driven corporation, is developing a growing portfolio of pharmaceutical products by applying the latest research from its own worldwide laboratories and from collaborations with eminent scientific organizations. Headquartered in Indianapolis, Indiana, USA, Lilly provides answers – through medicines and information – for some of the world's most urgent medical needs.

www.lilly.com



The Pharmaceutical Research and Manufacturers of America (PhRMA) is a voluntary, non-profit association representing leading global research-based biopharmaceutical companies. PhRMA's members are dedicated to discovering medicines that enable patients to lead longer, healthier, and more productive lives. Since 2000, PhRMA member companies have invested approximately \$550 billion in the search for new treatments and cures.

PhRMA is committed to working as a partner with governments, patients and other stakeholders to meet the shared goal of expanding patient access to quality healthcare through innovative, sustainable solutions. While every country is unique and tailored approaches will be required, there are common challenges and opportunities faced by countries at all stages of implementing universal health coverage (UHC). Accordingly, PhRMA supports efforts to:

- Ensure all citizens have fair and meaningful access to essential healthcare services: PhRMA recognises that many governments are striving to achieve equity in access to health services, including the quality of the services and financial protection for people using health services. To that end, PhRMA supports multi-sectoral efforts to increase access to a basic package of essential, quality healthcare services, with the government providing, at a minimum, a public safety net for the most vulnerable populations.
- Improve health outcomes and quality of care through effective and efficient use of available resources: PhRMA supports government consideration of diverse financing and reimbursement options to meet the healthcare needs of all citizens, and is willing to work closely with governments to find long-term solutions. PhRMA is well positioned to share best practices and tools to help increase efficiencies for policy makers and payers and improve patient access to healthcare services. In addition, PhRMA supports working with governments to articulate a clear vision for quality in healthcare to help implement national frameworks for continuous quality improvement and better population health.
- Encourage flexible, patient-centred approaches to facilitate healthcare financing and delivery: PhRMA believes that UHC efforts should put patients at the centre. As such, UHC implementation should include key stakeholders such as patients, provider groups, payers, manufacturers, distributors, academics, and policymakers at all levels of decision-making to identify fundamental healthcare needs and guarantee that services delivered reflect patient needs and expectations. PhRMA believes that the highest quality and most affordable healthcare is delivered when patients are empowered with options to make the best decisions for their healthcare needs.

www.phrma.org

Superior Sponsors



The treatment of millions of seriously ill patients worldwide depends on biologic medicines. However, as with other therapies, product quality and availability have been affected by manufacturing issues. Considered a worldwide leader in the research, development and manufacturing of complex biological therapies, Amgen strives to reliably deliver high-quality medicines that matter to patients.

For more than three decades, Amgen has been at the forefront of modern medicine. We take our commitment to patients seriously. That's why we make significant investments in our state-of-the-art manufacturing facilities, robust processes and an experienced and engaged workforce.

Looking to the future, Amgen is a leader in the next generation of biotech manufacturing. By applying new standards to many of our global operations, we are able to implement simpler, more efficient ways to provide vital medicines to an increasing numbers of patients.

www.amgen.com



The Pharmaceuticals Division of Novartis is recognised worldwide for the innovative products, services and solutions we provide to patients, physicians and healthcare organizations. This growing business works to change the way medicine is practised by following the science to deliver the right treatment to the right patient at the right time. The division researches, develops, manufactures, distributes and sells branded pharmaceuticals used to treat diseases and conditions across a variety of therapeutic areas, including: auto-immunity, cardiovascular, dermatology, infectious diseases, metabolism, neuroscience, oncology, ophthalmology, respiratory, rheumatology, and transplantation.

Our current product portfolio includes more than 50 key marketed products, many of which are leaders in their respective therapeutic areas. In 2013, the division achieved several major regulatory approvals in the US, Europe, Japan and Canada, including three US FDA Breakthrough Therapy designations. Our product development pipeline has 144 projects in various stages of clinical development.

Novartis believes in the human dimension of patients and engages with patients' organizations and advocates to improve the wellbeing and quality of life of people living with a serious illness. We listen to patients' organizations and advocates in line with our areas of focus to understand the experience of people living with a serious illness. As a result of this understanding, we endeavour to respond better to their needs and cooperate with them not only to enhance the capabilities of patients' organizations to serve the people they represent, but also to develop shared solutions around common goals.

www.novartis.com

Commended and Satellite Reception Sponsor



Medtronic

Medtronic is the global leader in medical technology – alleviating pain, restoring health, and extending life for millions

of people around the world. Medtronic Philanthropy focuses on expanding access to quality chronic disease care among underserved populations worldwide, in addition to supporting health access initiatives in communities where Medtronic employees live and give. Medtronic Philanthropy and its partners take a holistic view of existing healthcare systems and the barriers that interrupt the continuum of care. We aim to strengthen health systems by advancing policies, empowering patients and leveraging care-givers and front line health workers to enable people living with chronic disease to successfully manage their condition.

www.medtronic.com

Bag Sponsor



The National Health Council is the only organization that brings together all segments of the health community to provide a united voice for the more than 133 million people living with chronic diseases and disabilities and their family caregivers.

Made up of more than 100 national health-related organizations in the United States, its core membership includes approximately 50 of the nation's leading patient advocacy groups, which control its governance. Other members include professional and membership associations, nonprofit organizations with an interest in health, and major pharmaceutical, medical device, health insurance, and biotechnology companies.

The National Health Council brings together diverse stakeholders within the health community to work for healthcare that meets the personal needs and goals of people with chronic diseases and disabilities.

www.nationalhealthcouncil.org

Exhibitor



BIO is the world's largest trade association representing biotechnology companies, academic institutions, state biotechnology centers and related organizations across the United States and in more than 30 other nations. BIO members are involved in the research and development of innovative healthcare, agricultural, industrial and environmental biotechnology products.

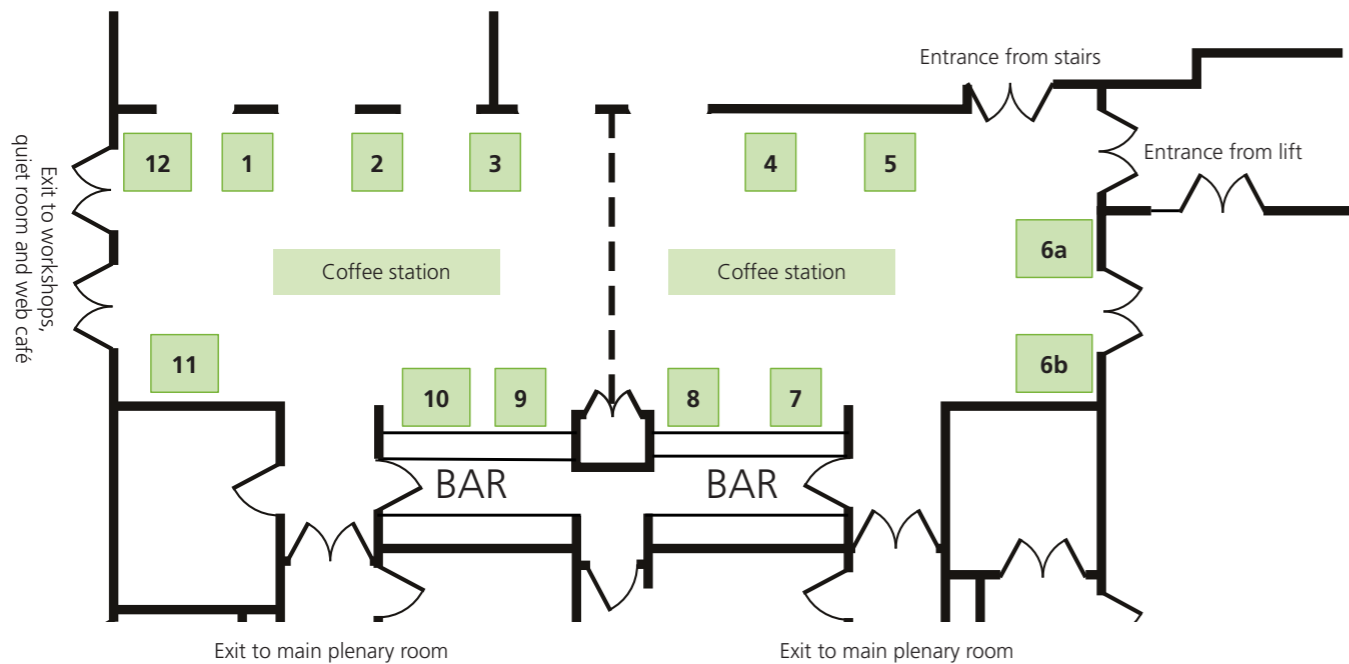
www.bio.org



Exhibition Layout

IAPO Members

Windsor & Eton



Organization	Stand No.	Organization	Stand No.
Biotechnology Industry Organization (BIO)	1	Medtronic	3
Eli Lilly	5	Miituu	11
IAPO	9	Novartis	12
IAPO Members Area	10	Registration Desk	6a & 6b
International Hospital Federation (IHF)	4	World Dental Federation (FDI)	2
Janssen	7	World Health Organization (WHO)	8

Congress Bursary Scheme for IAPO Members: IAPO is committed to broadening the participation of patients' organizations from all over the world at the Global Patients Congress. The bursary scheme is designed to assist with the attendance costs of a representative of an IAPO member organization that would otherwise not be able to participate. Bursaries were awarded through an application process and the following members received a bursary:

- Conceive/CONCEBIR, Argentina
- Association of Community Pharmacists of India
- Heart to Heart Foundation, Thailand
- Best Medicines Coalition, Canada
- Hydrocephalus Association, USA
- Platform Health in Dialogue, Portugal
- Moroccan Federation Supporting People with CKD & Organ Transplantation
- Center for Regional Policy Research & Cooperation 'Studiorum', Macedonia
- Health Consumers Alliance of South Australia
- Salvadoran Association for Cancer Prevention (ASAPRECAN), El Salvador
- CHEN Patient Fertility Association, Israel
- PLAN Health Advocacy and Development Foundation, Nigeria
- Venezuelan Federation of Associations of People with Learning Disabilities and Their Families

Subsidised Congress Registration Fees for IAPO Members: IAPO works to build the capacity of members through all of our events and activities. To assist members to attend the 6th Global Patients Congress, we are delighted to say that on this occasion, we were able to offer one free place to all IAPO members.

IAPO Full Members*

International

- Alagille Syndrome Alliance www.alagille.org
- Alzheimer's Disease International www.alz.co.uk
- Confederation of Meningitis Organisations www.comoonline.org
- Global Colon Cancer Alliance www.globalcoloncancer.com
- International Consumer Support for Infertility Patient Leader Network www.icsi.ws
- International Diabetes Federation www.idf.org
- International Dupuytren Society www.dupuytren-online.info
- International Federation of Psoriasis Associations www.ifpa-psy.org
- International FH Foundation www.fh-foundation.org
- International Patient Organisation for Primary Immunodeficiencies www.ipopi.org
- International Thalassaemia Federation www.thalassaemia.org.cy
- LIVESTRONG www.livestrong.org
- Multiple Sclerosis International Federation www.msif.org
- Parkinson Pipelines International www.pdpipeline.org
- World Alliance of Neuromuscular Disorder Associations www.wandaweb.org
- World Federation of Hemophilia www.wfh.org
- World Federation of Incontinent Patients www.wfip.org
- World Headache Alliance www.w-h-a.org
- World Hepatitis Alliance www.worldhepatitisalliance.org

Regional

Africa

- Africa Psoriasis Organization www.psoriasisafrika.org
- Community Health and Information Network www.chainproject.co.ug

Europe

- Association of European Coeliac Societies www.aoecs.org
- European AIDS Treatment Group www.eatg.org

- European Federation of Crohn's and Ulcerative Colitis Associations www.efcca.org
- Global Alliance of Mental Illness Advocacy Networks Europe www.gamian.eu
- Iatrogenic Europe Unite Alliance Foundation www.ieu-alliance.eu
- LUPUS EUROPE www.lupus-europe.org
- Rare Diseases Europe www.eurordis.org

Latin America and the Caribbean

- Latin American Network of Psoriasis www.latinapso.org

North America

- Easter Seals Inc. www.easterseals.com

National

Argentina

- Argentine Cystic Fibrosis Association www.fipan.org.ar
- Cherchen Yaich Civil Association www.cherchenaich.org.ar
- Civil Association for the sick of Psoriasis www.aepso.org
- Conceive www.concebir.org.ar

Australia

- ACCESS Australia Infertility Network www.access.org.au
- Association of Genetic Support of Australasia www.agsa-geneticsupport.org.au
- Australian Pain Management Association Inc. www.painmanagement.org.au
- Consumers Health Forum of Australia www.chf.org.au
- Fabry Support Group Australia Inc. www.fabry.com.au
- Health Care Consumers' Association of the ACT www.hcca.org.au
- Health Consumers Alliance of South Australia www.hcasa.asn.au
- Health Consumers' Council Inc (WA) www.hconc.org.au

Bosnia and Herzegovina

- Citizen Association for fight against diabetes 'ZENICA'

Brazil

- Brazilian Leukemia and Lymphoma Society www.abrale.org.br

Bulgaria

- Association of Patients with Kidney Diseases and Friends www.apbz.eu
- Association 'Women Without Osteoporosis'

- Bulgarian Association for Patients' Rights Defense www.patient.bg
- The National Patients' Organization www.npo.bg

Canada

- Asthma Society of Canada www.asthma.ca
- Best Medicines Coalition www.bestmedicines.ca
- Canadian Arthritis Patient Alliance www.arthritis.ca/capa
- Canadian Organization for Rare Disorders www.cord.ca
- Consumer Advocare Network www.consumeradvocare.org
- Infertility Awareness Association of Canada www.iaac.ca
- The Canadian Continence Foundation www.canadiancontinence.ca

China

- Beijing Association of Alzheimer's disease and related disorders www.baad.org.cn
- Hong Kong Alliance of Patients' Organizations www.apmho.org
- Retina Hong Kong www.retina.org.hk

Colombia

- Foundation Support of Patient with Psoriasis www.fundapso.org

Croatia

- Coalition of Associations in HealthCare www.kuz.hr
- Croatian Association for Patients' Rights www.pravapacijenata.hr

Cyprus

- Cyprus Association of Parents & Friends of Children with Heart Disease www.pediheart.org.cy
- Panycyprian Heart Patients' Association Patients' Rights Movement

Czech Republic

- Adam Czech Republic www.adamcr.cz
- Association of Individuals Afflicted by Civilization Diseases in the Czech Republic www.spcch.cz
- Czech Association of Patients www.pacienti.cz
- Diagnoza CML Civic Society www.diagnoza-cml.cz

Denmark

- Danish Cooperation of Patient Organisations www.pfsdk.dk

Estonia
Estonian Cancer Society
www.cancer.ee

Finland
Finnish Migraine Association
www.migreeni.org

Germany
German Pain League
www.schmerzliga.de

Ghana
Mental Health Society of Ghana
www.mehsog.org

Sharecare Ghana
www.sharecare4u.org

Greece
Society of Volunteers against Cancer
www.agaliazo.gr

Guatemala
Association for Children with Growth Problems
www.facebook.com/asociacion.procrece

Heroes of Hope Association

Hungary
Association of Hungarian Diabetic Patients
www.macosz.hu

Hungarian Coeliac Society
www.coeliac.hu

Hungarian Osteoporosis Patient Association
www.obme.hu

India
Dakshayani and Amaravati Health and Education
www.dakshamahealth.in

Ireland
Diabetes Ireland
www.diabetes.ie
Irish Patients' Association
www.irishpatients.ie
Patient Focus
www.patientfocus.ie

Israel
CHEN Patient Fertility Association
www.amotatchen.org

Italy
Italian Endometriosis Association
www.endoassoc.it

Japan
Fertility Information Network, Japan
www.j-fine.jp
HOPE project
www.kibou.jp
Osaka City University Hospital Cancer Patient Support Club
www.cscginnan.com
Pulmonary Hypertension Association
www.pha-japan.ne.jp

Liberia
Liberian United Youth for Community Safety & Development

Lithuania
Council of Representatives of Patient's Organizations of Lithuania
www.pacientutaryba.lt

Malawi
Global Hope Mobilization
www.glohomo.org

Patient and Community Welfare Foundation

Mexico
Health, Rights and Justice
Mexican Association Against Psoriasis
www.asociacionpsoriasis.com.mx

Mexican Federation of Hemophilia
www.hemofilia.org.mx

Morocco
Moroccan Federation Supporting People with Kidney Insufficiency and Organ Transplantation

Netherlands
Council of the Chronically Ill and the Handicapped in the Netherlands
www.cg-raad.nl

New Zealand
New Zealand Organisation for Rare Disorders
www.nzord.org.nz

Nigeria
Association of Women Living with HIV/AIDS in Nigeria

Community Development Alliance
www.comdeval.org

Diabetic Association of Adamawa

Foundation for Good Health and Wellbeing Initiative

Network of People Living with HIV/AIDS in Nigeria
www.nepwhan.net

PLAN Health Advocacy and Development Foundation

Positive Health Media Initiative

Positive Life Against HIV and AIDS Nigeria

Pakistan
Alzheimer's Pakistan
www.alz.org.pk
Jahandad Society for Community Development
www.jscd.org.pk
Thalassaemia Patients & Parents Society of Pakistan
Thalassaemia Society of Pakistan
www.thalassaemia.org.pk

Peru
Esperanza
www.esperanza.org
National Association of Patients on Dialysis and Transplantation

Philippines
Philippine Alliance of Patient Organizations

Scleroderma Society of the Philippines, Inc

Poland
European Society for Health Promotion PRO SALUTEM
www.pro-salutem.edu.pl

Federation of Polish Patients
www.federacjapp.pl

Patients Safety Foundation
www.patientsafety.ntx.pl

Polish Diabetes Association
www.diabetyk.org.pl

Portugal
Platform Health in Dialogue
www.anf.pt

Portuguese Diabetes Association
www.apdp.pt

Romania
Association PAVEL
www.asociatiapavel.ro

SANOHEP Romania
www.sanohep.ro

Russian Federation
Russian Union of Patients' Organizations
www.patients.ru

Slovakia
Association for Patients' Rights in Slovak Republic
Kardioklub SK
www.kardioklub.sk

Slovenia
Cancer Patients Association of Slovenia
www.onkologija.org

Pulmonary and Allergy Patients Association of Slovenia
www.dpbs.si

UP Hope Association of Slovenia Helping Drug Addicts
www.drustvo.up.si

South Africa
Patient Health Alliance of Non Governmental Organisations
www.phango.org.za

South African Depression and Anxiety Group
www.sadag.org

Spain
Association of Heart Patients of 12th October Hospital
www.corazon12.org

Asturian Rheumatology League
www.ligareumatologicaasturiana.com

Cordobesa Association of Patients Affected by Spondylitis
www.espondilitis.info

Foundation for Heart Disease in Young People
www.menudoscrazones.org

Madrid Association for Rheumatoid Arthritis Patients
www.amapar.org

National Arthritis Coordinating Committee
www.conartritis.org

Psoriasis Action
www.acciopsoriasi.org

Spanish Association Against Osteoporosis
www.aecos.es

Spanish Association of Patients with Heart Valves
www.anticoagulados.com

Spanish Confederation of Families of Patients with Alzheimer's and Dementia
www.ceafa.es

Spanish Federation for Heart Transplant Patients
www.fetco.es

Spanish Federation of Anticoagulated Associations
www.feasan.com

Spanish Heart Patients Association

Sri Lanka
Lanka Alzheimer's Foundation
www.alzlanka.org

Taiwan, Province of China
Taiwan Health Reform Foundation
www.thrf.org.tw/EN/index.asp

Turkey
Mucopolisaccharidosis and Related Lysosomal Storage
www.mpsturk.com

Uganda
Action Group for Health Human Rights and HIV/AIDS
www.aghauganda.org

Epilepsy Support Association Uganda
www.epilepsy.org.ug

Joyce Fertility Support Centre Uganda
www.joycefertility.org

National Care Centre

Sickle Cell Association of Uganda
www.sickleccluganda.org

The AIDS Support Organisation
www.tasouganda.org

The National Organisation for People Living with Hepatitis B

Uganda National Health Consumers/Users' Organisation
www.unhco.or.ug

Uganda Womens' Cancer Support Organization

Ukraine
All Ukrainian Public Organization Stop Hepatitis
www.hvstop.org

United Kingdom
BackCare
www.backcare.org.uk
Epilepsy HERE (Help Education & Research for Epilepsy)
www.epilepsyhere.org.uk

Friends of the Royal London Hospital for Integrated Medicine
www.savenhshomeopathy.org

Headstart4Babies
www.headstart4babies.org

INPUT
www.input.me.uk

Narcolepsy Association UK
www.narcolepsy.org.uk

National Concern for Healthcare Infections

National Voices
www.nationalvoices.org.uk

Pain UK
www.painuk.org

Pelvic Pain Support Network
www.pelvicpain.org.uk

Syncope Trust And Reflex anoxic Seizures
www.stars.org.uk

The Butterfly Group
www.thebutterflygroup.org.uk

The Lee Spark NF Foundation
www.nfsuk.org.uk

The Patients Association
www.patients-association.org.uk

USA
Alpha 1 Foundation
www.alphaone.org

American Autoimmune Related Diseases Association
www.aarda.org

American Chronic Pain Association
www.theacpa.org

American Diabetes Association
www.diabetes.org

Asthma and Allergy Foundation of America
www.aafa.org

Consumers Advancing Patient Safety
www.patientsafety.org

Hydrocephalus Association
www.hydroassoc.org

Interstitial Cystitis Association
www.ichelp.org

Kidney Cancer Association
www.kidneycancer.org

National Health Council
www.nationalhealthcouncil.org

National Multiple Sclerosis Society
www.nationalmssociety.org

Platelet Disorder Support Association
www.pdsa.org

Venezuela
Venezuelan Federation of Associations of People with Learning Disabilities and their families
www.fevedi.org

Newborn Screen and Phenilketonuria
www.tamizyfenil.org

Venezuelan Association for Haemophilia
www.avhemofilia.com

Zambia
Bethesda Zambia

IAPO Associate Members*

International

Cochrane Consumer Network
www.cochrane.org/consumers

International Painful Bladder Foundation
www.painful-bladder.org

Thrombosis Research Institute
www.tri-london.ac.uk

Regional

Europe
European Lung Foundation
www.europeanlung.org

Healthcare Compliance Packaging Council of Europe
www.hcpc-europe.net

Picker Institute Europe
www.pickereurope.org

National

Afghanistan
Afghan Society Against Cancer
www.cancer.com.af

Life Saving Organization for Afghanistan

Argentina
Natali Dafne Flexer Foundation
www.fundacionflexer.org

Bulgaria
Center for Protection of Rights in Healthcare
www.czpz.org

Cameroon
Action for Humane Hospitals
www.acthu.org

Canada
Cancer Advocacy Coalition of Canada
www.canceradvocacy.ca

Colombia
SIMMON Foundation
www.simmoncancer.org

Egypt
Breast Cancer Foundation of Egypt
www.bcfе.org

El Salvador
Salvadoran Association for Cancer Prevention
www.cancerelsalvador.org

Georgia
Georgian Alliance for Patient Safety
www.gesafety.org

India
Association of Community Pharmacists of India
www.acpi.in

Consumer Online Foundation
www.consumerconexion.org

Japan
Health and Global Policy Institute
www.hgpi.org/en

Specified Nonprofit Corp. Hiroshima Cancer Support
www.hiroshima-cs.jp

Kenya
Regional Society for Blood Transfusion Kenya

Macedonia (The former Yugoslav Republic of)
Center for Regional Policy Research & Cooperation 'Studiorum'
www.studiorum.org.mk

Mexico
Ale Asociacion, Private Assistance Institution
www.asociacionale.org

Nigeria
LiveWell Initiative
www.livewellng.org

Pakistan
Hamza Foundation Welfare Hospital
www.hamzafoundationhosp.org

Peru
Peruvian Patient Network
www.redperuanadepacientes.org.pe

Taiwan
Taiwan Women's Link
twl.ngo.org.tw

Thailand
Heart to Heart Foundation
www.nhso.go.th

United Kingdom
Arrhythmia Alliance
www.hearhythmcharity.org.uk

Nursing & Midwifery Council
www.nmc-uk.org

Safer Medicines Trust
www.safermedicines.org

USA
National Alliance for Caregiving
www.caregiving.org

Zambia
Advocacy on Human Development

* List as of 12 March 2014



Declaration on Patient-Centred Healthcare

Patient-centred healthcare is the way to a fair and cost-effective healthcare system

Health systems in all world regions are under pressure and cannot cope if they continue to focus on diseases rather than patients; they require the involvement of individual patients who adhere to their treatments, make behavioural changes and self-manage. Patient-centred healthcare may be the most cost-effective way to improve health outcomes for patients.

To us, the International Alliance of Patients' Organizations, the essence of patient-centred healthcare is that the healthcare system is designed and delivered to address the healthcare needs and preferences of patients so that healthcare is appropriate and cost-effective. By promoting greater patient responsibility and optimal usage, patient-centred healthcare leads to improved health outcomes, quality of life and optimal value for healthcare investment.

Patients', families' and carers' priorities are different in every country and in every disease area, but from this diversity we have some common priorities. To achieve patient-centred healthcare we believe that healthcare must be based on the following **Five Principles**:

1. Respect

Patients and carers have a fundamental right to patient-centred healthcare that respects their unique needs, preferences and values, as well as their autonomy and independence.

2. Choice and empowerment

Patients have a right and responsibility to participate, to their level of ability and preference, as a partner in making healthcare decisions that affect their lives. This requires a responsive health service which provides suitable choices in treatment and management options that fit in with patients' needs, and encouragement and support for patients and carers that direct and manage care to achieve the best possible quality of life. Patients' organizations must be empowered to play meaningful leadership roles in supporting patients and their families to exercise their right to make informed healthcare choices.

3. Patient involvement in health policy

Patients and patients' organizations deserve to share the responsibility of healthcare policy-making through meaningful and supported engagement in all levels and at all points of decision-making, to ensure that they are designed with the patient at the centre. This should not be restricted to healthcare policy but include, for example, social policy that will ultimately impact on patients' lives. See IAPO's Policy Statement at: www.patientsorganizations.org/involvement

4. Access and support

Patients must have access to the healthcare services warranted by their condition. This includes access to safe, quality and appropriate services, treatments, preventive care and health promotion activities. Provision should be made to ensure that *all* patients can access necessary services, regardless of their condition or socio-economic status. For patients to achieve the best possible quality of life, healthcare must support patients' emotional requirements, and consider non-health factors such as education, employment and family issues which impact on their approach to healthcare choices and management.

5. Information

Accurate, relevant and comprehensive information is essential to enable patients and carers to make informed decisions about healthcare treatment and living with their condition. Information must be presented in an appropriate format according to health literacy principles considering the individual's condition, language, age, understanding, abilities and culture. See IAPO's Policy Statement at: www.patientsorganizations.org/healthliteracy

To achieve patient-centred healthcare at every level in every community, the International Alliance of Patients' Organizations is calling for the support and collaboration of policy-makers, health professionals, service providers and health-related industries to endorse these Five Principles and to make them the centre of their policies and practice. We call upon all stakeholders to provide the necessary structures, resources and training to ensure that the Principles outlined in this Declaration are upheld by all.

© 2006 IAPO. All rights reserved. This policy was adopted in February 2006 by IAPO following member consultation and agreement by the Governing Board. Further information about Patient-Centred Healthcare including evidence for its impact and barriers to its practice can be found in the IAPO publication *What is Patient-Centred Healthcare?: A Review of Definitions and Principles* (IAPO, 2005) at: www.patientsorganizations.org/pchreview Contact IAPO at: info@patientsorganizations.org



International Alliance of
Patients' Organizations

A global voice for patients

49–51 East Road, London N1 6AH, United Kingdom
Tel: +44 20 7250 8280 Fax: +44 20 7250 8285 Email: info@patientsorganizations.org
www.patientsorganizations.org

Company no. 8495711 Registered charity no. 1155577