



International Alliance of
Patients' Organizations

A global voice for patients

**'Innovation improving sustainable access:
boosting your reach and impact'**

7th Global Patients Congress

Attendee Handbook

9-11 April 2016 • Selsdon Park Hotel, South London, UK

www.iapo.org.uk/GPC2016 #GPC2016

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Welcome

Dear Congress Delegate,

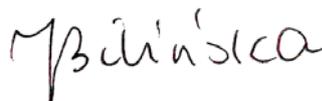
It is my great pleasure, on behalf of IAPO's Governing Board and Staff, to welcome you to the 7th Global Patients Congress, the global event for patient leaders and others working to improve the lives of patients worldwide. The top priority for many patients' organizations is to improve their advocacy and campaigning capability. This is not easy in today's complex global and national environments, and that's why this year's Congress will focus on 'innovation improving sustainable access: how to boost your reach and impact'.

We will be show-casing innovation from IAPO's membership, from the smallest members to the largest, and demonstrating changes that improve sustainable access to health services and therapies. This can boost the reach (by more diverse service users) and impact (in effectiveness, efficiency and equity) of every organization and health system. Delegates will be able to exchange ideas, engage with regional colleagues and draw on the energy and expertise of others to enhance their work.

In addition, we will have keynote speakers and panelists, who will offer delegates new perspectives on patient access and involvement, from both patient-led and industry-led initiatives. Above all, Congress offers delegates the opportunity to meet or catch up, exchange information and ideas, and to provide vital input to IAPO's work and direction.

As IAPO Chair I look forward to meeting and speaking with you, listening to your needs and working towards mutual aims over the coming days. I am particularly pleased to welcome new members, who are crucial in helping us to strengthen the global patients' voice - I hope you will benefit from our orientation and networking sessions in particular. The IAPO Governing Board and Staff will be on hand during the Congress should you need any support or information.

Best wishes,



Jolanta Bilińska
IAPO Chair



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.

Members

IAPO has 250 members, representing 47 disease areas and 67 countries, 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.

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

Innovation improving sustainable access: boosting your reach and impact

7th Global Patients Congress: Programme

Innovation to achieve universal, patient-centred and sustainable access to health

193 UN member states agree, as a component of the Sustainable Development Goals 2030, to establish sustainable universal health coverage (UHC) to ensure healthy lives and well-being for all.

All IAPO member organizations worldwide, as expressed in the Declaration on Patient-Centred Healthcare and Principles on Universal Health Coverage, support the proposition that the only way to achieve sustainable UHC is for patients to participate as partners in the development and delivery of healthcare.

Innovation in every aspect of health will be featured at IAPO's 7th Global Patients Congress in 2016.

Innovation and collaboration are needed to transform health systems to achieve universal and sustainable health coverage, deliver better outcomes for patients, and to meaningfully engage patients as stewards in their own health and well-being.

Participants will gain insights into innovative restructuring of healthcare delivery and much more. Patients and patients' organizations are innovatively taking charge of everything from virtual patient

communities to crowd-funding for drug discovery and clinical trial participation.

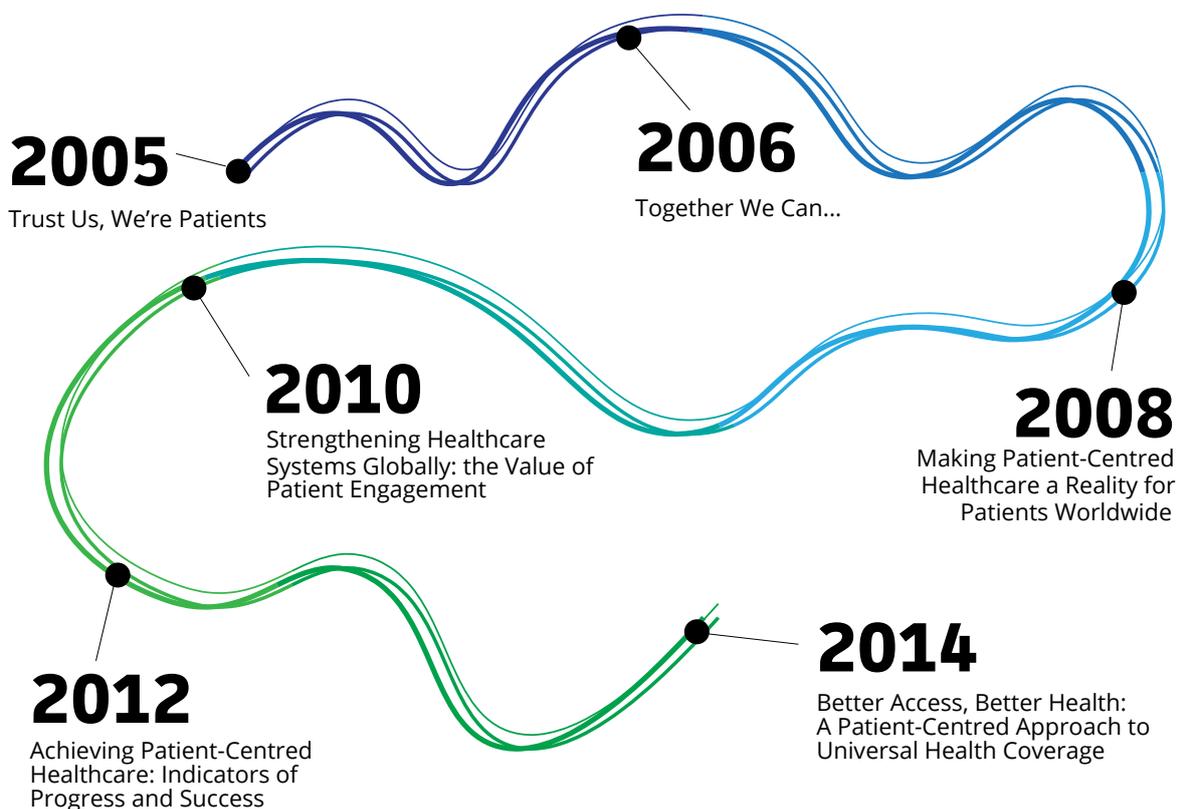
Patient-engagement and advocacy within re-organization of health systems, including financing and service delivery structures, are essential to assuring quality, safety, efficiency, effectiveness and sustainability of healthcare.

How will participants benefit?

Participants will focus on **innovation** and what works, **peer learning** across countries and disease areas, and **collaboration**. The Congress will deliver knowledge, tools, and skills that participants will take back to their own member communities, enabling them to engage as active partners in today's complex global and national environments. Participants will share and learn from the experience of peers and experts. They will take away relevant, practical and inspiring ideas they can apply to their communities to achieve greater impact and better outcomes for patients around the world.

Participants will:

- **Input** into IAPO direction and priorities
- **Showcase** member initiatives, promoting peer-to-peer learning
- **Stimulate** thinking around innovation and impact



With thanks to the Congress sponsors

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Novartis is a global healthcare company inspired by patients. This inspiration motivates us to revolutionize the research, development and manufacturing of quality, innovative treatments that help people live longer, with a better quality of life giving more time to do the things that matter to them. To do our best for patients we do not accept the status quo. We work to enable patient access worldwide so that patients and society can benefit as quickly as possible. The depth and strength of our pipeline enables us to change the practice of medicine and to bring more breakthroughs with real benefits to patients and society. We partner with people and organizations around the world because by working together we can make a greater difference. We continually challenge ourselves to the highest standards of compliance, integrity and performance in all that we do to ensure a sustainable future of innovation for patients, society and Novartis. www.novartis.com

Gold Sponsor: Johnson & Johnson / Janssen



Caring for the world one person at a time inspires and unites the people of Johnson & Johnson. We embrace research and science - bringing innovative ideas, products and services to advance the health and well-being of people. Our approximately 128,000 employees at more than 265 Johnson & Johnson operating companies work with partners in healthcare to touch the lives of over a billion people every day, throughout the world. www.jnj.com



Janssen Pharmaceutical Companies of Johnson & Johnson are dedicated to addressing and solving the most important

unmet medical needs of our time, including oncology (e.g. multiple myeloma and prostate cancer), immunology (e.g. psoriasis), neuroscience (e.g. schizophrenia, dementia and pain), infectious disease (e.g. HIV/AIDS, hepatitis C and tuberculosis) and cardiovascular and metabolic diseases (e.g. diabetes). Driven by our commitment to patients, we develop sustainable, integrated healthcare solutions by working side-by-side with healthcare stakeholders, based on partnerships of trust and transparency.

www.janssen-emea.com

Silver Sponsor: Medtronic



The Medtronic Foundation focuses on expanding access to healthcare among underserved populations. We recognize the power of patients in driving policy and societal change. We support efforts that provide direct support to patients, and strengthen health systems to better meet their needs. We ensure patients remain at the center of the effort to improve access, giving them the voice they deserve through organizations such as IAPO. Through the Global Heroes and the Bakken Invitation programs, we celebrate patients who take charge of their health while contributing to their communities, and we share their stories to help educate and inspire other patients to manage their health condition.

www.medtronic.com/foundation





Carol Stevenson

Event Coordinator Director, Novus Marketing & Event Management

carol.stevenson@novusmem.co.uk

Carol has over 12 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 Marketing and Event Management in 2009, a consortium of freelancers who specialize in healthcare events and marketing management, 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), as well as helping many start-up companies in the health sector shape and execute their marketing strategies.

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 **Maria James**, Delegate Manager, **Kate Ray**, Exhibition Manager and **Carolyn Seaman**, Speaker & AV Manager.

Onsite Information

Admission To The Congress

Access Entitlements

On Saturday 9 April 2016, 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. Member delegates, especially those attending Congress for the first time, are encouraged to register and attend the orientation briefing at 08:30. Registration will begin at 08:00.

Registration for all other stakeholders will open from 08:00-08:45 on Sunday 10 April 2016. The Congress programme and exhibition on Sunday 10 April and Monday 11 April 2016 are open to all delegates.

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

Badges

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

Blue - IAPO Member

Black - Invited Guest (Non-Member)

White - IAPO Governing Board Member

Yellow - Industry Partner/Sponsor

Red - IAPO Staff/Novus Staff

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 Cedar Suite 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 by handing it into the Registration Desk at the end of the Congress.

Registration Desk

The registration desk is located in the Cedar Suite Foyer which lies between the main plenary room (Cedar Room) and the Tempus Bar. If you have any queries during the Congress, please make your way to 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 fees at the registration desk during the afternoon refreshment break on Saturday (Day 1: Members Day).

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

Networking Opportunities During The Congress

Orientation Briefing

Saturday 9 April – 08:30

An orientation session for IAPO members will be held at 08:30 in the Aragon Room on Saturday 9 April 2016. The session will offer members an introduction to the 7th Global Patients Congress and an opportunity to identify how to get the most from the event. The session will take the form of 'speed-updating', providing new and returning delegates the chance to get to know each other and share experiences. This activity will be an excellent opportunity for members to discuss expectations for the weekend ahead and get guidance on making the most of their time at Congress.

Welcome Reception

Saturday 9 April – 17:00

All delegates are invited to attend the Welcome Reception on Saturday 9 April, which will be held in the Solarium and the outdoor terrace. If the weather is bad, we will also use the Surrey Room. This will give delegates the chance to meet with others in a relaxed setting. Refreshments, including wine, soft drinks and canapés, will be served during the reception.

Small-group Networking Sessions

Sunday 10 April 14:30-15:15

This session will enable delegates to network with others, or host and participate in small group discussions on topics of their choice that relate to the Congress themes. The topics could be region- or disease-specific depending on interest, and it will offer the opportunity to hear a range of perspectives from delegates across the world.

Break-out areas will be provided for groups. Further details will be given throughout the Congress.

Pre-Gala Dinner Drinks Reception

Sunday 10 April – 19:00

A drinks reception will be held in the Solarium and the outdoor terrace before the Congress Dinner. All delegates are invited.

Gala Dinner

Sunday 10 April – 20:00

Delegates are invited to attend the Gala Dinner on Sunday 10 April as IAPO's guest. This will be hosted in the Cedar Room and will feature a range of interactive activities. 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.

Lunch

Lunch will be provided each day throughout the Congress – times vary, please refer to the programme.

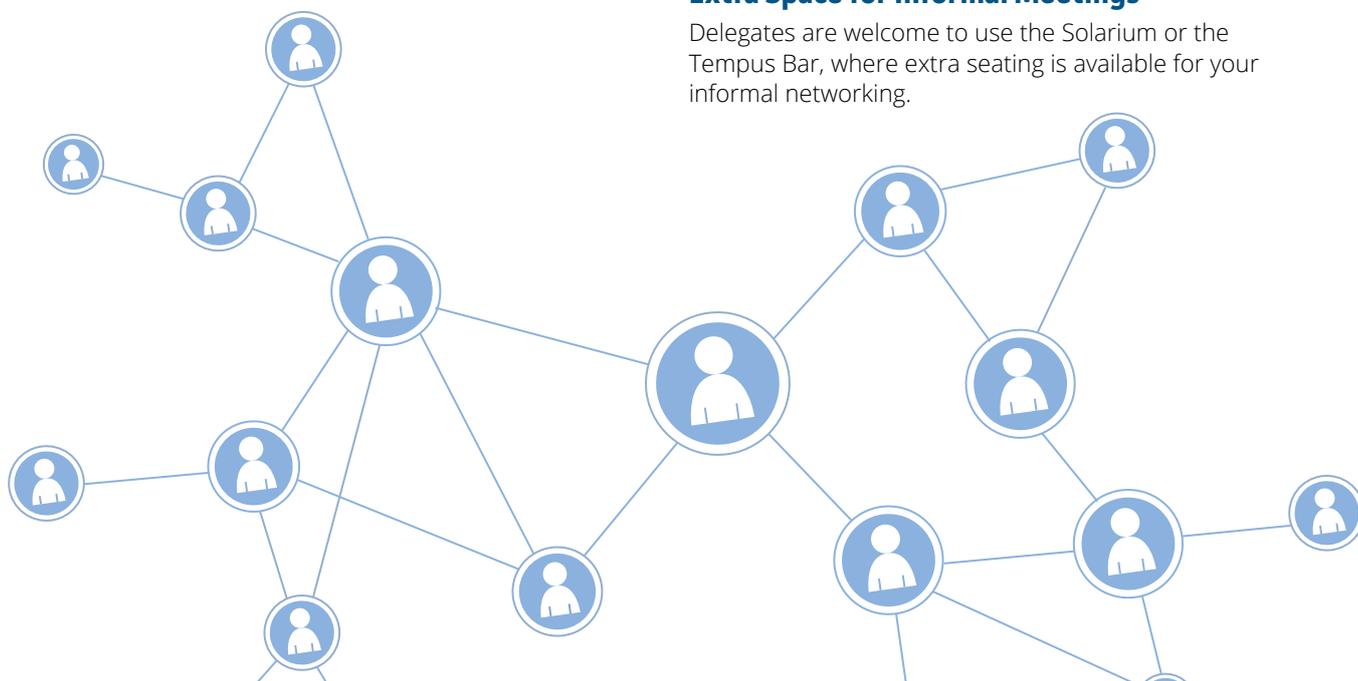
Lunch will be served in the main hotel restaurant, located on the ground floor of the hotel behind the reception. Any dietary requirements that we have been informed about will have been catered for, but please do let the serving staff, IAPO or Novus staff know if you have any specific requests.

IAPO Member Gallery

The IAPO Member Gallery, located in the Surrey Room, will showcase a selection of photographs, posters and films submitted by IAPO members to an open call for submissions. The aim of the gallery is to illustrate patient-centred healthcare through the work of IAPO members. The gallery will profile IAPO members and offer a visual experience of patient-centred healthcare.

Extra Space for Informal Meetings

Delegates are welcome to use the Solarium or the Tempus Bar, where extra seating is available for your informal networking.



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 Congress planning for future years. A paper evaluation and evaluation cards will also be available at the event.

Onward Travel

The Selsdon Park Hotel operates a shuttle bus service to take delegates to East Croydon train station after the Congress. The bus will operate every hour on the hour from 07:00 until 19:00. Please enquire at the hotel reception. Trains from East Croydon go direct to Gatwick Airport.

To book a taxi from the Congress back to Gatwick Airport, we recommend Station Cars (+44 208 660 6000). You can book either privately by phone or through the hotel concierge.

Other Information

Accessibility

All public areas at the Selsdon Park Hotel are accessible by ramp to wheelchair users, with the exception of the Kent Room, which is step-access only. There is a disabled toilet on the ground floor outside the Cedar Suite.

Communications and Media

An IAPO Congress media pack is available online to support your media activities during the 7th Global Patients Congress. We encourage you to send relevant information to your media contacts. The media pack can be downloaded from the Congress website: www.iapo.org.uk/GPC2016

Social Media at the Congress

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

www.twitter.com/IAPOVoice

(please add this hashtag to your tweet: #GPC2016)

Concierge

Should you have any queries regarding the hotel and its facilities, the Selsdon 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.

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.

Emergencies

In the event of an emergency, please contact a member of staff from Novus or IAPO at the Registration Desk, or a member of 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.

Hearing Loop

There is a portable induction loop facility to cover all of the Congress meeting rooms and in the hotel reception area. Please set your hearing aid to "T".

Internet

There is free Wi-Fi access for all delegates using smart phones or tablets. Internet access will be via the Principal Hayley network, which is complimentary throughout the hotel. To log in to the network, connect to the network then open your browser. The screen should refresh to the PH homepage, where you should log in as a "Conference guest" using a username and password that can be requested either from the Congress registration desk or the Hotel reception.

Quiet Room for Prayer and Meditation

Located in the hotel reception area in front of the Terrace Suite, the Hospitality Suite offers a quiet space for Congress delegates who need to pray or have quiet time for reflection and meditation throughout the event.

Programme at a glance

Day 1 • IAPO members • SATURDAY 9 April 2016

Time	
From 08:00	Registration
08:30-09:00	1. Orientation
09:15-10:30	2. IAPO Annual General Meeting
<i>Refreshments in the Surrey Suite</i>	
11:00-11:15	IAPO Annual General Meeting continued
11:15-11:25	3. Welcome and introduction
11:25-12:00	4. Keynote speaker
12:05-12:40	5. Keynote speaker
<i>Lunch in the Terrace Restaurant</i>	
14:00-15:30	6. Workshop sessions: Patients' organization-led innovation
<i>Refreshments in the Surrey Suite</i>	
15:45-16:30	7. Plenary panel
16:30-16:45	8. Member Workshop feedback and takeaways
17:00	9. Drinks reception



Day 2 • Members, partners and others • SUNDAY 10 April 2016

Time	
08:00-08:45	10. Registration for newcomers
08:45-09:00	11. Welcome
09:00-10:30	12. Keynote addresses
10:30-11:30	13. Plenary Panel
<i>Refreshments in the Surrey Suite</i>	
12:00-13:30	14. Workshop sessions (Please note that Workshop D starts at 11:45)
<i>Lunch in the Terrace Restaurant</i>	
14:30-15:15	15. Small group networking and discussion groups
<i>Refreshments in the Surrey Suite</i>	
15:30-16:15	16. Plenary Panel
16:15-16:30	17. Workshop feedback and takeaways
16:30-17:00	18. Group Photo Opportunity!
19:00	DRINKS AND GALA DINNER

Day 3 • Members, partners and others • MONDAY 11 April 2016

Time	
08:45-08:55	19. Welcome
09:00-10:40	20. Plenary Panel
<i>Refreshments in the Surrey Suite</i>	
11:00-12:00	21. Closing keynote speakers
12:00-12:10	Closing comments and next steps
<i>Lunch and depart</i>	

The invitation-only Partners Meeting begins at 12:30 with a working lunch in the Sir Edward Heath Room.

Full Programme

Day 1 • IAPO members • SATURDAY 9 April 2016

Time

From 08:00 **Registration**
Cedar Foyer

08:30-09:00 **1. Orientation**

Aragon
Room

Meet and greet with Governing Board Chair **Jolanta Bilińska**

An orientation session for IAPO members will be held at 08:30 in the Aragon Room after registration. The session will offer members an introduction to the 7th Global Patients Congress and an opportunity to identify how to get the most from the event. The session will take the form of 'speed-updating', providing new and returning delegates the chance to get to know each other and share experiences. This activity will be an excellent opportunity for members to discuss expectations for the weekend ahead and get guidance on making the most of their time at Congress. Participants will also have a chance to meet IAPO Governing Board Chair Jolanta Bilińska.

09:15-10:30 **2. IAPO Annual General Meeting**

Cedar Room

Annual meeting of IAPO members, for election new Governing Board members; receiving and approving the 2015 financial statements and annual report; appointing IAPO's auditors; presentation of future IAPO plans.

Refreshments in the Surrey Suite

11:00-11:15 **IAPO Annual General Meeting continued**

Cedar Room

Announcement of the five newly-elected IAPO Governing Board members.

11:15-11:25 **3. Welcome and introduction**

Cedar Room

Jolanta Bilińska (IAPO Governing Board Chair) and **Kawaldip Sehmi** (IAPO Chief Executive) will welcome members and set the scene for the Congress theme: innovation to achieve universal, patient-centred and sustainable access to health. They will look back on progress since the last Congress, and highlight what's coming up including member examples of initiatives, collaborations and networks that are delivering real benefits for patients. There will be time for member questions and discussion about what you are looking forward to and what you hope to take away from the Congress to put in to practice within your own patient communities.

11:25-12:00 **4. Keynote speaker**

Cedar Room

Nicolas Sireau (Chair, AKU Society UK) on new approaches to community mobilisation and increasing impact

Nick Sireau is Chair of the AKU Society UK. He is an Ashoka Fellow, and has taken a lead role in social innovation and entrepreneurship to benefit people in low and middle income countries including health equity and improving access and treatments for rare diseases.

The AKU Society is a small but influential patient group helping patients with AKU, also known as Black Bone Disease. Through a strategy of collaboration, it has created an international consortium that is now leading the quest for a treatment for this ultra rare disease. From fundraising to networking and scientific research, the experience led to the creation of a new non-profit called Findacure, which seeks to help rare disease patient groups scale up fast and find treatments for their diseases. This talk will describe the journey and provide advice for patient groups wishing to drive drug development.

12:05-12:40 **5. Keynote speaker**

Cedar Room

Peter Boyle (FRSE FFPH FRCPS FRCP FMedSci) on responding to the challenge of rising global cancer rates

Peter Boyle is an internationally well-known cancer prevention advocate and researcher. He has contributed to the fields of tobacco and lung cancer, breast cancer and prostate cancer and will highlight how innovation can respond to the challenge of rising global cancer rates, particularly in lower and middle-income countries.

Lunch at the Terrace Restaurant

14:00-15:30 **6. Workshop sessions: Patients' organization-led innovation**

Patients' organizations innovating together for greater impact

Members will share practical examples and discuss successful innovation. In this first workshop session, attendees will choose from one of four small group discussions featuring successful member initiatives.

6a. Innovation in rare or stigmatized diseases and disorders and treatment (Kent Room – please note that this room has a few steps at the entrance)

Facilitator & Chair: **Anders Olauson**, European Patients Forum and Ågrenska, Sweden

When a family has a child with a chronic illness everything changes. All images of the future and attitudes, goals and visions change forever and in most cases disappear. Unfortunately, no new family pictures, maps or proposed approaches or networks appear that understand their new life. Through our international cooperation we have discovered that this situation is the same regardless of where in the world a woman gives birth to a child with a chronic illness, and especially a child with a rare diagnosis. The Ågrenska family programme through its holistic approach has proved to be unique. The aim of the session is to disseminate these experiences, as well as develop further possible ways forward in all other areas of research, treatment, social interactions etc. on which a person with a rare diagnosis depends.

Rubby Chawla, Indian Patients Society for Primary Immunodeficiency

Following personal family tragedy Rubby's husband and she formed an organization to support other patients and families: the Indian Patients Society for Primary Immunodeficiency (IPSPI), in 2004. Since then they have never looked back and have successfully advocated for Primary Immunodeficiency Disorders (PID). IPSPI has successfully organized and facilitated awareness campaigns and workshops educating medics and the general public. They continue to counsel patients' families as there is lot of social stigma on diagnosis. Their main motto is 'early diagnosis to save lives'. They have raised their voice emphasising on Universal Health Coverage as a basic Human Right and have pursued government advocacy at central and state levels for coverage and access to treatment. They have been successful in getting the treatment coverage from the government in various states, and for the first time in December 2014 PID was addressed by the federal government.

Other speakers:

Joshua Wamboga, Uganda Network of AIDS Service Organisations (UNASO)

6b. Building a regional movement with impact: Latin America (Sir Edward Heath Room)

Facilitator & Chair: **Eva Maria Ruiz de Castilla**, Esperantra, Peru

A longstanding IAPO and Esperantra advocate for patient involvement and patient rights in Latin America, Eva Maria will highlight the work and continuous strengthening of IAPO's network of members in Latin America, including challenges and particular successes as they have worked to build collaborative action.

Migdalia Denis, Latin Pulmonary Hypertension Latin Society (SLHP), Latin America

The SLHP is the only patient organization of this nature created to and for patients and their family members suffering from PH in the region. The organization is directed by a team of professionals (mostly patients) who are part of the board of directors and represent several countries in Latin America. The impact of PH is profound towards people who have the illness as well as towards their families and the community as a whole. Due to the lack of knowledge for an early diagnosis and the few available treatments in Latin America, the objective of the SLHP is to support other organizations of patients established in Latin America and, through them, help the patients in the region suffering from the disease. Furthermore, the organization supports the search for doctors and medical services with experience in the treatment of this disease. The Pulmonary Hypertension Latin Society is a link that connects the different organizations, facilitating the exchange of knowledge and scientific support among the society.

Carolina Cohen, Alianza Latina, Latin America

Founded in 2006 with the goal of representing and empowering non-profit organizations that support patients in Latin America, today Alianza is composed of 110 members that operate in 21 countries (17 of them being in Latin America). Coordinated by ABRALE, Alianza Latina is a successful regional initiative that benefits more than 380,000 patients. The main goal of the network is to provide the necessary instruments for the empowerment, qualification, and development of the member organizations, making Alianza Latina the largest interlocutor facing the health organizations and governments in Latin America.

Marco Espíldora H., CancerVida, Chile

In 2020 cancer will be the leading cause of death in Chile. Also, in five years, 1 in 4 Chileans will be aged over 60 years. Cancer is closely related to the aging population and it is known that age increases the risk of breast cancer in women and prostate cancer in men. CáncerVida and the National Institute of Geriatrics of Chile (INGER) in 2015 organized a Day to raise awareness with cancer patients and their families, "Cancer and aging." "The importance of the day was to highlight the need to put care for the elderly at the centre, in the context of cancer, and help them understand the entire course of the disease, ranging from diagnosis to treatment and then palliative care in cases that are not curable. This means that the patient has been supported from the beginning, is not abandoned", Dr Cristina Gastó, Chief of the Palliative Care Unit of INGER.

6c. Building effective and innovative networks and campaigns for greater impact (Cedar Room)

Facilitator & Chair: **Hussain Jafri**, Alzheimer's Pakistan

Katharina Kovacs Burns, Best Medicines Initiative, Canada

Patients and patient groups across Canada have expressed concerns regarding different aspects of healthcare, including access, wait times, drug programmes and coverage. They queried 'measuring' of the healthcare system and wanted to provide decision makers the evidence they needed to influence practices and policies from the patient point of view. Surveys, focus groups and validation pilots identified patient-experience indicators and measures to highlight in evidenced-based campaign messages. Patients identified 12 important indicators for healthcare overall, 9 for Primary Healthcare, 15 for Continuing Care and 36 for drug programmes; aimed at macro (healthcare system), meso (practice and service delivery) and micro (patient/family/caregiver) levels. This benchmarking evidence will complement patient stories and advocate to health systems and decisions makers about patients' self-identified needs.

Gi-jong An, Korean Alliance of Patients' Organizations (KAPO)

KAPO, a leading grass-roots patients' organization in Korea, created the Patient Shouting Café in 2012 with its unique slogan of "Shouting, Healing and Solutions." In the first opportunity of its kind, Korean patients are speaking themselves about their own stories and sufferings in the healthcare system, healing and bonding emotionally, and seeking solutions from advisory experts with 100 listeners including patients, media and other stakeholders. These real-world voices have a huge influence on key issues, shaping public opinions on the social agenda, and solving problems. The Patient Shouting Café plays an important role in building a bridge between a patient's issue and the legal system.

Anne Charlet, Lupus Europe

Poor adherence to treatment is a significant problem in lupus, with multi-factorial causes, some of which patients will not easily discuss with doctors. To capture insights and make appropriate recommendations, Lupus Europe brought together 10 European lupus patients, for 2 days of interactive group sessions, guided by facilitators with lupus themselves. A working definition of treatment and main factors for poor adherence were identified, and the findings were summarized in letters for the medical community and fellows living with lupus. The results of this patient panel on treatment also included 7 short videos on key issues when living with lupus and all elements that are used throughout the year for campaigns including World Lupus Day.

Flora Raffai, Findacure, UK

Findacure is an example of a successful initiative that is empowering patients through training, mentoring, and an online portal to enable them to take on the challenges of their conditions. There are 7,000 rare diseases, affecting 350 million people worldwide. Yet these conditions are largely overlooked due to the small patient numbers of each individual disease. Of the 7,000 conditions, only 200 have licensed treatments. Patients are often left with low health outcomes, suffering from debilitating diseases, kept from work or being active due to complications. This talk will explore the importance of empowering patients and patient groups in the rare disease field, where they can transform research strategies, provide crucial funding, and bring expertise about disease progression.

6d. Innovative collaborations to increase impact (Aragon Room)

Facilitator & Chair: **Mary Lynne van Poelgeest-Pomfret**, World Federation for Incontinence Patients

Bejon K. Misra, Consumers Online Forum, India

The Partnership for Safe Medicines (PSM) India Initiative was founded in 2010 by patient advocacy groups representing various facets of healthcare delivery system. The innovation was an information technology (IT) driven transparent process to build credibility and to protect the patients from unsafe medicines and improve accessibility to quality healthcare. The impact has been felt in the decision making process within the policy makers and the drug regulatory mechanism in India.

Kerstin Morrison, European Lung Foundation, UK & Europe

This session will be an introduction to the European Patient Ambassador Programme (EPAP). This is an online self-learning course for people affected by chronic conditions. The programme equips patients and carers with the knowledge and skills they may need for effective patient involvement in healthcare at every level. Participants will be able to see how the course works and get a demonstration of some of its interactive features. The session will also provide information about how useful patients have found the programme and what it helped them to achieve.

Ofra Balaban, CHEN (Patient Fertility Association), Israel

In Israel, the role of NGOs is so important to ensure systems work. Without the volunteering organizations the system cannot function at all. Laws are changing for the benefit of patients and this session will show what can be learnt from the Israeli case: what can and should be done internationally. CHEN participates in meetings; they speak with the members of the committees for new medication; they apply to the media with a loud and clear voice to affect decision-makers' decisions.

Gertrude Buttigieg, Malta Health Network

Malta is one of the smallest states in the world, but due to its strategic geographic position it has served in world history as the 'Nurse of the Mediterranean'. Malta has one of the newest hospitals in Europe. In 2008 the Malta Health Network (MHN) through partnership with Active Citizenship Network embarked on a nationwide campaign on the promotion of the European Charter of Patients' Rights. This drive has led to the concept of Patients' Rights being included in two of the most recent legislations introduced in Malta. What has MHN done to reach this stage and what are the future plans?

Joan Jordan, EUPATI patient representative, Europe

A computer scientist by trade, Joan's life was changed forever when she was diagnosed with Multiple Sclerosis at the same time as her son developed epilepsy. Over six years, she has become an involved patient and has tried her hand at blogging, participating in a clinical trial and advocacy. Joan will outline why she made this transition and the advantages of participating in your own healthcare decisions. She will talk about the European aspect of the EUPATI course and how side effects are managed in medicine R&D: "Help me help you!"

Refreshments in the Surrey Suite

15:45-16:30 **7. Plenary panel**

Cedar Room

Patients' organization-led innovation - what works?

In this Plenary Panel, participants will hear from speakers and have a facilitated discussion talking about what really works in patients' organization led innovation.

Introduction and facilitation of discussion: **Durhane Wong-Reiger**, Consumer Advocare Network, Canada

Panellists to include: **Mattias Wienold**, European AIDS Treatment Group and;

Penney Cowan, American Chronic Pain Association

16:30-16:45 **8. Member Workshop feedback and takeaways**

Cedar Room

Facilitator: **Joshua Wamboga**, Uganda Network of AIDS Service Organisations

17:00 **9. Members drink reception**

Surrey Suite

Day 2 • Members, partners and others • SUNDAY 10 April 2016

Time

08:00-08:45 **10. Registration for newcomers**

Cedar Foyer

On Days 2 & 3, IAPO members will be joined by additional Congress delegates who take an active role in driving forward innovation that can deliver benefits for patients, from industry, the research and academic community, and regional and global agencies at the forefront of health and health improvement.

08:45-09:00 **11. Welcome**

09:00-10:30 **12. Keynote addresses**

Cedar Room

Where are we on the journey towards Universal Health Coverage (UHC)?

This Plenary Panel and Congress participant discussion will consider how UHC innovation is helping to deliver sustainable access, including global perspectives on progress.

Facilitator: **Kawaldip Sehmi**, IAPO Chief Executive

Panellists to include: **Nittita Prasopa-Plaizier** Patients for Patient Safety Programme Manager, World Health Organization

10:30-11:30 **13. Plenary Panel**

Cedar Room

Exploring strengths and weaknesses of different approaches to innovation in Universal Health Coverage and Patient-Centred Healthcare

Facilitator: **Jolanta Bilińska**, IAPO Governing Board Chair

Panellists to include: **Joshua Wamboga**, Uganda Network of AIDS Service Organisations and **Robert Johnstone**, National Voices, UK

Refreshments in the Surrey Suite

12:00-13:30 **14. Workshop sessions**

Effective innovation in practice – demonstrating what works!

In this workshop session, participants will choose from one of four small group discussions.

14a. Innovation in training for action, and achieving demonstrable results *(Kent Room – please note that this room has a few steps at the entrance)*

Facilitator & Chair: **Penney Cowan**, American Chronic Pain Association

Tamás Bereczky, EUPATI, Europe

Representing the European AIDS Treatment Group, one of the larger patient organizations involved in EUPATI, Tamás Bereczky will give a brief introduction about the history and importance of this innovative and highly successful programme funded by the European Union. Outcomes for academia, industry, regulators and the patient community will be discussed. Advantages and shortcomings will be explored, and a short outlook into the future of the project will be outlined. The involvement of patients in biomedical research is essential. However, good ethical and scientific practices must be observed to avoid tokenism.

Mary Lynne van Poelgeest-Pomfret, World Federation for Incontinence Patients

Patient advocates and patient organizations are the prime source of ensuring innovative ways are brought into the various healthcare systems. To achieve this, the patient voice is paramount. Personal involvement in equality of access to healthcare is one such example. Becoming involved in working groups such as the Medical Technologies Group/Patient Dialogue has done much to streamline the understanding between the various stakeholders – industry, science and academia and patient organizations. Capacity-building and the desire to learn, especially when it comes to the new innovative aspects of healthcare today to achieve sustainability in the future, is a major step forward. Take for example the contribution of patients as end users when it comes to mobile/eHealth, digital health, internet of things, interoperability. All novel aspects with which patients and the public must become familiar in today's world.

Christine Janus, Global Skin/International Alliance of Dermatology Patient Organizations

Using 'Report Cards' for effective advocacy has been effective in the Canadian context: Report cards did something that hadn't happened before - they gave the patient voice in dermatology credibility and easier access to decision-makers who previously refused to meet or seriously consider patients' needs directly. Christine will explore why measuring and sharing access issues faced by patients in a report card can provide credibility for you as patient advocates and can help implement change. Facts are almost always respected and understood. Learn how to set up a Report Card, the dos and don'ts, key elements and how to build a supportive communication programme. Importantly, learn how using Report Cards can raise your organization's value to your stakeholders and establish your organization as a key partner for change.

Krystal Boyea, Diabetes Advocate and Spokesperson

A personal account from a young person with diabetes with extensive experience in patient representation and advocacy.

14b. Patient involvement in research: innovation in the drug development and access pathway (Sir Edward Heath Room)

Facilitator & Chair (5 mins): **Antonio Ciaglia**, IAPO

Alison Lightbourne, IAPO

Here we will highlight the collaborative work of IAPO in multi-stakeholder collaborative projects in Europe, in particular the Innovative Medicines Initiative (IMI) Get Real and PROTECT projects where we aim to influence industry, researchers and public bodies to better involve patients at all stages and to improve the research and medicines development pathway.

Jane Meijlink, International Painful Bladder Foundation

This presentation takes a brief look at the role that patients can and should play in standardisation of terminology and definitions, including guidelines, outlining the distinction between guidelines, pathways, taxonomies and standardisation of documents. Healthcare is a chain with multiple links, and standardisation of terminology and definitions can have an impact on every link in the chain and therefore a major impact on the patient, the patient's healthcare and ultimately the patient's whole family. Terminology and definitions have a research impact, a medical impact and a social/financial impact on the patient. Some of the pitfalls in the development of standard terminology can be avoided by involving patient representatives.

Ricardo C Santiago, Health Insight

Rede Mães de Minas (EUSAUDE for Maternal Health), is a maternal health project that includes the health analysis of the newborn up to 3 years old, and has been running in Minas Gerais Brazil since 2012. More than 40,000 pregnant women and relatives interested in the subject have been enrolled, and data on clinical and demographic aspects has been collected for three years. During the most active period of the web portal, more than 200,000 mothers were able to register, and there were more than 4 million visitors per year. From the data collected, they were able to confirm many health situations and adaptations to health habits and literacy that took place in the community, including acquisition of health knowledge measured with clinical questionnaires and, from the clinical perspective, they were also able to send to hospital about three women daily, with symptoms of high risk of clinical complications.

Other speakers:

Alan Nolan, Quintiles

14c. Innovation to expand access and strengthen health systems (Cedar Room)

Facilitator & Chair: **Kawaldip Sehmi**, IAPO Chief Executive

Kawaldip Sehmi, IAPO Chief Executive

When the WHO Framework Convention on Tobacco Control (WHO FCTC), entered into force on 27 February 2005, the world's first global public health treaty culminated an over 50 year-long global health advocacy campaign. The success of WHO FCTC was dependent upon the fact that it was an innovative whole-of-society and whole-of-government affair in the first instance, and it then gave pride of the place to the patients with non-communicable diseases (Cancer, Heart Disease, COPD): patients having no voice at all (laryngectomy patients) gave voice to the world's most successful and longest public health and social change campaigns.

Lars Ettarp, International Federation of Psoriasis Associations (IFPA)

The presentation will focus on how the IFPA managed, together with some WHO member states as interested partners, to influence WHO to adopt the Psoriasis Resolution in May 2014, and the challenges IFPA has faced thereafter. Before that Lars will describe how the IFPA managed to become a recognised and respected international patient organization, a unifying voice for psoriasis associations around the world, working on a global level for a better world for more than 125 million people around the world with psoriasis and psoriatic arthritis. Today IFPA has 55 national psoriasis organizations as members around the world.

Rebecca Stevens, Novartis Access Programme

The menace of noncommunicable diseases (NCDs) like cardiovascular diseases diabetes and cancer in the developing world is increasing. Chronic illnesses require early detection and long-term, ongoing treatment and society needs new ways to ensure access to medicines for NCDs in countries where people often have limited access to healthcare. The Novartis Access programme focuses on affordability and availability of medicines addressing four key NCDs: cardiovascular diseases, diabetes, respiratory illnesses and breast cancer.

14d: Meaningful engagement of patients and people in patient safety and health care quality improvement: The role of patient advocates (Aragon Room)

Facilitated by: **Nittita Prasopa-Plaizier**, Programme Manager, and

Felicity Pocklington, Consultant, Patients for Patient Safety Programme, Service Delivery and Safety Department, World Health Organization & **Hussain Jafri**, Alzheimer's Pakistan

This session is organized by the World Health Organization (WHO) through the Patients for Patient Safety (PPFS) programme of the Service Delivery and Safety (SDS) department. It aims to engage the participants in a discussion about how patient advocates, health professionals and policy-makers can help facilitate and encourage meaningful engagement of patients, families and the community in patient safety and healthcare quality improvement.

This session will provide perspectives from different stakeholder groups. The discussion will be centred on how countries can build on WHO's approach on engaging for patient safety and quality improvement, particularly on the patient advocate use of the patient experience 'story' for professional and organizational learning. Case studies on how WHO collaborates with patients and national organizations to facilitate the creation of a national network of patient advocates will be shared.

The participants will be encouraged to share ideas and possibilities on how patient advocates can engage and empower healthcare providers and policy-makers to partner with patients, families and the community engagement in service delivery and system re-design to achieving people-centred and quality UHC. The workshop will employ a combination of approaches to stimulate information sharing and interactive discussions for brainstorming issues, ideas and experience sharing. The scene setting presentation component will cover topics including:

- The WHO Global Framework on Patient and Family Engagement - what's your role?
- Meaningful engagement - what does it mean to you?
- Developing capacity for engagement - for patients and professionals
- Key issues, challenges and opportunities - what will it take to engage and make it meaningful?

Please note:
The WHO workshop
has a different start and
finish time - 11.45-13.45

Lunch at the Terrace Restaurant

14:30-15:15
Cedar Room

15. Small group networking and discussion groups

This session will enable delegates to network with others, or host and participate in small group discussions on topics of their choice that relate to the Congress themes. The topics could be region- or disease-specific depending on interest, and it will offer the opportunity to hear a range of perspectives from delegates across the world.

Break-out areas will be provided for groups. Further details will be given throughout the Congress.

Refreshments in the Surrey Suite

15:30-16:15
Cedar Room

16. Plenary Panel

Exploring approaches to innovation in patient involvement and access

In this afternoon's Plenary Panel, speakers will explore a range of different approaches on innovation in patient involvement and access.

Facilitator: **Penney Cowan**, American Chronic Pain Association

Victoria Pinkney-Atkinson, Patient Health Alliance of Nongovernmental Organisations, South Africa
Victoria will speak on the theme of patient involvement and access and highlight key learnings that work in collaboration from a patient perspective. Victoria will share how she believes innovation is about replicating successes.

Sylvie St-Laurent, Pfizer Inc.

Sylvie will describe Pfizer's creation of global RA specific platforms to increase the voice of RA patients in improving access and health outcomes as well as the ability of national groups to engage in complicated policy discussions on biosimilars.

16:15-16:30
Cedar Room

17. Workshop feedback and takeaways

Facilitated by: **Kawaldip Sehmi**, IAPO Chief Executive

16:30-17:00
Outside Terrace
(weather permitting)

18. Group Photo Opportunity!

19:00 **Drinks Reception and Gala Dinner**

Day 3 • Members, partners and others • MONDAY 11 April 2016

Time

08:45-08:55
Cedar Room

19. Welcome

Jolanta Bilińska, IAPO Governing Board Chair

09:00-10:40
Cedar Room

20. Plenary Panel

Exploring industry, pan-regional and research-led innovation

Facilitator and Chair: **Penney Cowan**, IAPO Board Member

Panellists to include: **Nathalie Bere**, European Medicines Agency (EMA); **Hilde Vanaken**, Janssen; **Katherine Beaverson**, Pfizer Inc.; **Dr Andy Bushell**, Novartis & **Kate Knobil**, GlaxoSmithKline

Refreshments in the Surrey Suite

11:00-12:00
Cedar Room

21. Closing keynote speakers

Exploring innovation by healthcare professionals and global NGOs in conflict areas

Facilitator: **Tessa Richards**, British Medical Journal

Stijntje Dijk, International Federation of Medical Students Associations

Safeguarding health personnel, students and society: what can we do? Enjoyment of the highest attainable standard of health and healthcare to all human beings is a fundamental right. However, with health workers and students falling under attack worldwide, necessary care cannot always be guaranteed. This keynote will address the need for collaboration between different sectors as both current and future health workforce, as well as patients and the general public who have key roles in influencing government decisions, to lead towards better disaster preparedness, regaining respect and knowledge on medical ethics and international health law, as well as to safeguard learning and working environments to retain health workers in conflict areas.

Bruce Eshaya-Chauvin, Health Care in Danger (HCiD) Project International Committee of the Red Cross (ICRC)

The HCiD project aims to make healthcare delivery safer around the world by mobilising experts to develop practical measures for decision-makers, military, humanitarian organizations and health professionals. The project is a response to a pressing humanitarian issue affecting thousands in armed conflicts and other emergencies: the violence against patients, health-care personnel and facilities and its negative impact on healthcare systems. This initiative has published several important tools including one on the "Ethical Principles in conflict and other emergencies". Produced by military and civilians, we hope patients' organizations can endorse it.

12:00-12:10
Cedar Room

Closing comments and next steps

Jolanta Bilińska, IAPO Governing Board Chair

from 12:10
Terrace
Restaurant

Lunch and depart

(IAPO Industry Partners, please note: Partners meeting to follow at 12:30 in the Sir Edward Heath room – working lunch provided)

Posters on display

IAPO members are invited to contribute to the Posters on display in the Cedar Foyer. Amongst those expected to be on display are the following:

Coeliac UK

“Social marketing and case finding strategies for coeliac disease (CD)”

Coeliac UK launched a campaign in 2014 to tackle underdiagnosis of coeliac disease (CD). The campaign adopted social marketing and case finding strategies to drive improvements in the diagnosis of CD, with a particular focus on younger adults and those from socioeconomically deprived backgrounds, where UK prevalence was lowest. The range of symptoms associated with CD, coupled with variation in how they are experienced, made people with undiagnosed CD difficult to find. Impactful images and video were created for social marketing that highlighted the most common symptoms of CD and encouraged people to take the next step toward diagnosis. An online platform with the UK's first online assessment for CD based on NICE Guidance was developed to provide triage and further information to those engaged with the campaign. Users of the assessment that reported symptoms of CD, related conditions or a family connection were signposted for further testing from a healthcare professional. Strategies trialling novel approaches to case finding for CD were also adopted. Coeliac UK delivered a series of outreach events and piloted the use of community pharmacy as a site for assessment, point of case testing and signposting for CD.

Dakshama Health

“A Patient Coalition: Successes and challenges”

Medicine and its dispensing is an age-old art with several streams existing in India. Dakshama Health was set up with the objective of bringing patient groups together across disease spectrums to build a strong patient voice that could represent and address the need for quality, safety and access in India. It aimed to address the financing for healthcare and influence policy for equitable distribution of resources. There is a positive momentum in this area and many patient groups are very active and welcomed the idea. The idea received a warm welcome and we have successfully built the Indian Association of Patient Groups (IAPG). The government is also positive and is welcoming such initiatives by including the Alliance in policy discussions and dialogues. Resources are however a major challenge as is getting the members to think around common interest areas. The composition of the members is very diverse and spread across the vast expanse of the country posing challenges for communication due to the multiplicity of languages

Fundación SIMMON

Throughout 2013 and 2014, Fundación SIMMON carried out and released the results of two research projects associated to breast cancer, access barriers and the need to include breast cancer as an event of interest in the national surveillance system. The first research project, “Barriers to healthcare access: Narratives of women with breast cancer in Colombia”, was carried out with the participation of 44 women from six NGOs - including SIMMON - from different regions, researchers from the FUCS University in Bogotá and a psychologist supplied by SIMMON. From the results of this research it was determined that despite the political efforts to improve healthcare for (breast) cancer patients, there are access barriers before which the system shows some degree of inability. The second research study, released in October 2014, “Breast cancer IS a disease in public health interest”, was funded through a grant awarded by the American Cancer Society, and was carried out by two researches in the areas of epidemiology, economics and social politics. The objective was to develop a technical-scientific document that could be used as guidance in the adoption of breast cancer as an event of interest in the National Public Health Surveillance System. These two studies have been key instrumental pieces in the Foundation's advocacy job. Research projects have proven to be useful tools in opening the dialogue with multiple health system actors around concrete issues and put forward proposal for improvement and change.

Rare Diseases International

RDI is the global alliance of people living with a rare disease of all nationalities across all rare diseases. It brings together national and regional rare disease patient organisations from around the world as well as international rare disease-specific federations. Its mission is to be a strong common voice on behalf of all people living with a rare disease around the world; to advocate for rare diseases as an international public health and research priority; to represent its members and enhance their capacities. RDI is a EURORDIS initiative, in partnership with the US National Organization for Rare Disorders (NORD), the Canadian Organization for Rare Disorders (CORD) and the Japanese Patient Association (JPA), with whom EURORDIS has signed Memorandums of Understanding that include the creation of RDI.

For further information

For the biographies of our governing board members, please visit: www.iapo.org.uk/governing-board

For the biographies of our speakers please see: www.iapo.org.uk/gpc2016-speakers

For a list of IAPO members please visit: www.iapo.org.uk/iapo-members

