

International Alliance of Patients' Organizations (IAPO) 3rd Global Patients Congress

20-22 February 2008, Hilton Budapest, Hungary

Patient-Centred Healthcare
Aligning healthcare systems with patients' needs around the world



Following the success of the first two IAPO congresses held in London and Barcelona, IAPO's 3rd congress was organized in Budapest, Hungary. This was a unique opportunity to involve patient advocates and healthcare organizations from Central and Eastern Europe and to provide a much needed boost to the endeavours of patient support groups in this region as well as worldwide. Regional organizations

supporting the congress were the Federation of Polish Patients, Coalition of Associations in Healthcare in Croatia, the Hungarian Federation of People with Rare & Congenital Diseases and the All-Ukrainian Council for Patients' Rights & Safety. With representatives present from the pharmaceutical industry, the World Health Organization, the European Commission Health & Consumer Protection Directorate General (SANCO) and other stakeholders, patient representatives had an ideal opportunity to network and make new contacts. The International Painful Bladder Foundation was represented by its chairman Jane Meijlink who also chaired two workshops for IAPO member organizations.

What is IAPO?

Established in 1999, IAPO is a unique global alliance representing patients of all nationalities across all disease areas and promoting patient-centred healthcare around the world. IAPO's members represent over 50 diseases areas and currently come from 41 countries worldwide. IAPO is supported by the World Health Organization (with which it has official relations) and the European Commission. IAPO's vision is that patients throughout the world are at the centre of healthcare. IAPO represents an estimated 365 million patients worldwide.

Patient-Centred Healthcare. Nothing about us without us!

IAPO's Declaration on Patient-Centred Healthcare outlines the principles necessary to address these issues and to achieve patient-centred healthcare as defined by patients' organizations worldwide.

This Declaration can be read at www.patientsorganizations.org/declaration and concerns:

- Respect for unique needs, preferences and values

- Choice and empowerment
- Patient involvement in health policy
- Access and support
- Information that is accurate, relevant and comprehensive.

These issues also formed the basis of its 3rd congress attended by patient representatives and stakeholders from around the world.

The first day of the congress was a members' day including the annual general meeting. This members' day focused on capacity building with a range of sessions in the form of workshops designed by members to meet members' needs. The workshops were an ideal way for new members to get to know existing members, to discuss their problems and successes, improve their knowledge and skills, learn how to tackle difficult issues and of course make a lot of new friends! One of the main aims of the congress is to build up the skills, knowledge and networks of IAPO patient representatives so as to ensure that they are well-informed, effective advocates at every level where healthcare decisions are made.



Photo: Workshop participants from around the world.

The congress itself opened on 21 February with top level plenary sessions on the future of healthcare: improving patient safety and the need for an international concerted effort to address the issue of patient safety, access to treatment and care, the need for high quality health information and meaningful patient involvement in health policy decision-making.

Top keynote speakers

Keynote speakers were Mr Ton Hoek, General Secretary, International Pharmaceutical Federation (FIP) (WHPA), Sir Liam Donaldson, Chair of the World Alliance for Patients Safety & Chief Medical Officer (UK), Dr Andrzej Rys, Director Public Health & Risk Assessment,

European Commission DG SANCO and Dr Linda Milan, WHO Western Pacific Regional Office Director, Building Healthy Communities & Populations.

Inequality of access to healthcare around the world was a recurring theme. The lack of access to healthcare is one of the leading causes of ill health. Ton Hoek asked delegates: “What use is the best medicine if there is no access to it?”

In many countries there is a critical shortage of healthcare workers. The WHO has launched the Global Health Workforce Alliance dedicated to finding solutions to the growing health workforce crisis around the world. There are shortages of physicians, pharmacists, dentists and nurses and also shortages of hospital beds in many parts of the world. The affordability of medicine is a major issue. And this is an aspect with which we in the PBS/IC world are very familiar.

Patient safety and medical errors are a major cause for concern. Sir Liam Donaldson gave a number of poignant examples of instances where medical errors, communication failure and errors in drug administration led to deaths. As the poster of the World Alliance for Patients Safety states: to err is human, to cover up is unforgivable and to fail to learn is inexcusable. Tragic events should serve as a catalyst. We must identify common causes of errors and anticipate them. The right training of healthcare professionals is vital if errors are to be prevented.

Counterfeit medicines are a huge problem, together with incorrectly stored medicine and drugs that have passed their expiry date.

Patients were advised to always check their prescription and medication strength.

Dr Rys explained that even within the expanding EU, there are growing health gaps, with many people in the newer member states having poor access to medical treatment. The EU wants to help patients across the European Union obtain the care they need and to improve the effectiveness and efficiency of healthcare systems overall. The EU also wishes to address the lack of information and uncertainties regarding patients’ rights and quality of treatment abroad which can prevent patients from seeking out these opportunities. It also intends to provide clarification regarding the rights of patients to reimbursement. Dr Rys also stressed that the European Commission’s health policies are designed around the patient and that patients and patient representatives are key stakeholders in the development of those policies.

When talking about what the patient wants in the Asian-Pacific region, the aspects raised by Dr Linda Milan would really apply to patients worldwide:

- Better communication & information
- Full disclosure of diagnosis & prognosis
- Shared treatment decision-making
- Privacy
- Respect & politeness
- Service provider discipline
- Assurance
- Emotional support

- Feeling of being listened to
- Health practitioner knowledge about disease and treatment

Patient information at different levels of literacy

Much attention was focused on information and how to provide information for people at all levels of literacy. Regina Kamoga from CHAIN Uganda told delegates about the different methods of providing health information to those unable to read in Uganda using drama, singing and dance. Discussions on how to write patient information at the very simplest level revealed that this is no easy task and a skill in itself. The language used must suit the target audience and at the most basic level should be jargon-free. This is quite a challenge for us in the PBS/IC world where diagnostic procedures are complex and may involve cystoscopy, hydrodistension and biopsy. Explaining these in the most basic terms requires a great deal of expertise.

The information a patient organization needs to provide starts with the patient in the centre and has a kind of rippling effect in ever-widening circles extending to the general public, healthcare professionals, government authorities and more besides. A description should be given to the patient of the condition, its prevalence, diagnostic procedures and treatment options. An informed patient is able to make choices and participate in treatment decision-making.

This was a very successful IAPO congress. The next IAPO congress will be held in 2010.

Join IAPO!

We encourage support groups around the world to join IAPO.

Useful websites:

IAPO:

<http://www.patientsorganizations.org/>

IAPO publications, briefing papers and policy statements:

<http://www.patientsorganizations.org/showarticle.pl?id=810;n=109>

IAPO: Patient-Centred Healthcare Portal:

<http://www.patientsorganizations.org/showarticle.pl?id=20&n=310>

European Commission Health & Consumer Protection Directorate General (SANCO)

http://ec.europa.eu/dgs/health_consumer/index_en.htm

World Health Organization

www.who.int

International Pharmaceutical Federation:

www.fip.org

Patient representatives relaxing and networking at the IAPO congress.

