



# Trust us - we're patients!

London, United Kingdom, 29 February 2005 – “Trust us – we’re patients” was the overwhelming theme of the International Alliance of Patients' Organizations (IAPO) first ever Global Patients Congress, held in London from 25-27 February 2005. Bringing together IAPO's member patients' organizations from around the world, over 70 patient leaders from a diverse range of therapeutic backgrounds exchanged valuable skills and experiences and worked together developing strategies to bring patients to the centre of healthcare systems.

The Congress was opened by Harry Cayton, Director for Patients and the Public at the Department of Health. He shared a personal message from The Rt. Hon. Dr. John Reid M.P. Secretary of State for Health, UK, “The Secretary of State has asked me to welcome you to this first Global Patients Congress and to England. The Government in the UK is strongly committed to the involvement of patients and the public in decisions about their personal health and health care and as citizens in the planning and improvement of health services. Active patient organisations are vital partners for governments, health professionals and health care providers in improving health and increasing choice for all. The Secretary of State hopes you have a productive and stimulating conference.”

Harry Cayton introduced the ideas, “Trust me, I’m a patient!” and “Nothing about us without us”, which resonated with the delegates and were central to the themes of the Congress - patient involvement and partnerships. Patient delegates at the Congress quickly established a strong and mutually supportive community and, equally, they were keen to develop understanding and collaborative partnerships with healthcare policy-makers, professionals, providers and companies. The Congress brought together 28 representatives of these groups helping to build networks and foster collaborations for the future.

On the Saturday, the EU Commissioner for Health and Consumer Protection, Markos Kyprianou, headed a high-level international panel of policy-makers, patient representatives, providers and industry representatives that considered the benefits and challenges of patient involvement in healthcare policy, systems and delivery. Following the session, Albert van der Zeijden, Chair of IAPO, expressed his appreciation of the panellists' commitment to patient involvement and emphasized that “Patient involvement is often dependent on the goodwill of a few individuals. I know that with support and commitment from others we can make it the rule, rather than the exception”.

On Sunday, IAPO's valued partners, the International Council of Nurses (ICN), the International Pharmaceutical Federation (FIP), the World Medical Association (WMA) as well as the International Federation of Medical Students Associations (IFMSA), shared their perspectives on the challenges health professionals experience and the need for collaboration to promote understanding between professionals and patients. Contributing to this issue, the World Health Organization (WHO) launched their new publication “Preparing a Healthcare Workforce for the 21st Century: The Challenge of Chronic Conditions”. The report outlines five core competencies of patient-centred healthcare, partnering, quality improvement, information and communication technology and public health perspective. Dr JoAnne Epping-Jordan, Coordinator, Health Care for Chronic Conditions, WHO, commented, “These competencies do not replicate or preclude established core competencies (evidence-based care, ethical care), nor profession-specific competencies. Rather, they augment existing knowledge and skills to provide better outcomes for chronic conditions”. Dr Epping-Jordan added, “It is entirely fitting to launch this publication at IAPO's first Global Patients Congress in the presence of contributors to the publication, IAPO, the European Respiratory Society (ERS), ICN, FIP and WMA”.

The ideas and actions generated at the Congress are being fed into written guidelines to encourage meaningful patient involvement in healthcare policy, systems and delivery. IAPO will also launch a Manifesto for Patient-Centred Healthcare later this year, communicating the principles of patient-centred healthcare reflected in the meeting and by patients' organizations globally.

Commenting on the success of the Congress, Enrique Silver, IAPO Board Member and President of the Uruguayan Cystic Fibrosis Association commented, “This Congress has shown how much can be achieved when patients' organizations from around the world come together. I have experienced an amazing sense of community and shared values between patient leaders from Africa, the Americas, Asia and Europe.” John Walsh, President and Chief Executive of the Alpha-1 Foundation in the United States added, “We worked hard together this weekend to identify the importance of the close collaboration of all stakeholders. The Congress provided a forum for all of us to identify the most important challenges we face to improve healthcare and structure the dialog for collaboration of all stakeholders moving forward. The open exchange and synergy generated helped each of our organizations by providing the framework to create initiatives to support our common goals. I think it is critical that we continue to foster global communications and look forward to making additional progress at the Congress next year”.



*Delegates talk at the meeting*