



International Alliance of
Patients' Organizations

A global voice for patients

Membership Guide



Putting patients at
the centre of healthcare

what our members say...



The unique global alliance of IAPO spans countries and continents to bring together the 'patient voice' in healthcare and policy reform. Being a part of this enhances our ability to connect with other patient-centred organizations around the world who hope to inspire, empower and create effective change for the patient.

LIVESTRONG, IAPO Member



There is the concrete help of IAPO to get up-to-date information and to find ways to take part in the forming of health politics, a very valuable thing for me. But what is most meaningful for me is the feeling of being a member of the big family of patients all over the world – this is what strengthens me in fighting never-ending problems.

Josef Mrázek, Vice-president of the Czech Association of Patients, IAPO Member



IAPO is a wonderful source of knowledge and expertise in all aspects of patient advocacy, supporting patients' organizations worldwide.

**Lynne van Poelgeest-Pomfret, Vice President,
World Federation of Incontinence Patients, IAPO Member**



Patients all around the world have much in common. Their starting position is often different, but they all want access to quality care and doctors who are listening to them and see them as individuals rather than suitable objects for treatment.

Albert van der Zeijden, Chairman, Dutch National Council of the European Disability Council, IAPO Founder Member



We have a strong partner (in IAPO) to represent our needs, able to work on all kinds of healthcare issues globally and give us feedback locally... It shows others that patients' organizations are valuable and recognised partners to work with.

Tomasz Szelagowski, Federation of Polish Patients, IAPO Member

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welcome

to the International Alliance of Patients' Organizations (IAPO) Membership Guide. As an IAPO member or prospective member, this guide will help you to take advantage of the many benefits and opportunities available. It will also provide you with an introduction to how IAPO and our member organizations work together to promote patient-centred healthcare around the world.



Introducing IAPO: a global voice for patients

IAPO is the only global alliance representing patients across all disease areas and promoting patient-centred healthcare around the world. Our Full Members are patients' organizations working at the international, regional, national and local levels to represent and support patients, their families and carers. Our Associate Members are other health-related, non-profit organizations working towards patient-centred healthcare. IAPO has over 200 members, representing over 50 disease areas and over 50 countries, and has a network that represents an estimated 365 million patients.

The impact of IAPO's voice is created by the diversity and breadth of members which incorporates the views of international and umbrella disease associations with those of community-based, self-help groups. IAPO advocates on a wide range of healthcare policy areas, from overarching patient issues, such as patient safety, to specific issues such as health literacy. Our goal is to engage with all patients' organizations committed to patient-centred healthcare.

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 realising active partnerships with patients' organizations, advocating internationally with a strong patients' voice on relevant aspects of healthcare policy and building cross-sector alliances.

Contact us by email at: membership@patientsorganizations.org

Why join IAPO?

IAPO is made up of patient groups committed to improving the lives of their communities and advocating for patient-centred healthcare around the world. IAPO members learn from each other and are better able to work towards their individual vision and to meet their patient group needs. By joining together, the patient voice is stronger and IAPO members collectively impact health policy from the highest international levels to local healthcare delivery.

The contribution of members is essential to all of IAPO's activities. IAPO offers many education and development opportunities to enhance the capacity of member organizations. Members can



take advantage of printed materials, toolkits, workshops and forums through in-person regional and international meetings as well as through electronic media, such as the IAPO website and our Facebook and Twitter pages. You can learn about IAPO education and development activities elsewhere in this guide and stay informed about specific opportunities through our website and newsletter.



What we offer members

- Collaboration with IAPO and patients' organizations around the world
- Engagement in international and regional advocacy, including with the World Health Organization (WHO) through our healthcare policy activities
- Capacity building and training – attend workshops and events, and access online resources exclusive to IAPO members
- Visibility – reach a global audience of healthcare stakeholders and promote your activities and events through our publications, newsletter and website
- Monthly member newsletter, exclusive to IAPO members, with information on our international healthcare policy activities and events

What IAPO members can offer

- Join a global patient movement to promote patient-centred healthcare around the world
- Shape IAPO's policy positions by responding to consultations
- Sign up to the Declaration on Patient-Centred Healthcare
- Share information on your work, including policy activities, newsletters and annual reports, which can inform IAPO's and other members' work
- Disseminate IAPO information and materials with your constituency

Make the most of your IAPO membership

- Participate in IAPO Committees, such as the Global Patients Congress Advisory Committee
- Participate in IAPO's Annual General Meeting, remotely or in person
- Consider nomination for the IAPO Governing Board
- Promote your IAPO membership by adding the IAPO logo to your website and materials
- Seek IAPO auspices for your events and publications
- Take part in IAPO events, including the Global Patients Congress and sponsored workshops and forums (with reduced or no fees for IAPO members)
- Promote IAPO's Declaration and healthcare policy statements in your advocacy work



We became a member of IAPO in 2008 and for the first time we started to think about the possibility to create coordinated actions with organizations from other diseases in our country. To start working, we focused on IAPO's principles and started networking in our country to make them known. We believe that IAPO has helped us by widening our vision and our mission.

Estela Maria Chardon, Coordinator, Concebir, Argentina, IAPO Member

Declaration on Patient-Centred Healthcare

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

1. Respect for unique needs, preferences and values
2. Choice and empowerment
3. Patient involvement in health policy
4. Access and support
5. Information that is accurate, relevant and comprehensive

IAPO members have used the Declaration to advocate for patient-centred healthcare in their local, national or regional contexts. As well as the Declaration, IAPO's policy statements provide patients' organizations with advocacy tools.

Read the full Declaration and pledge your support at:

www.patientsorganizations.org/declaration



The Alliance has been promoting the concept of patient-centred healthcare using IAPO's Declaration. We have translated the Declaration into both traditional and simplified Chinese and have advocated for the government in Hong Kong and major public healthcare providers to accept patient representatives to participate at all levels of decision-making processes, from policy formulation and planning through to implementation and review. Through our advocacy work, we have achieved greater patient involvement in decision-making processes.
KP Tsang, IAPO Governing Board Member and Chairman, Alliance for Patients Mutual Help Organizations, Hong Kong, IAPO Member



activities and projects

IAPO undertakes numerous activities and projects – these range from developing policy statements to capacity building workshops and training, engagement in international policy-making, and networking. For more information please visit: www.patientsorganizations.org/planofactivities

Global Patients Congress

IAPO's biennial Global Patients Congress provides a unique opportunity for patient advocates, across diseases and across borders, to come together and participate in an exciting agenda which will help to foster global networks, develop practical skills and enable engagement and understanding of key policy issues affecting patients in the international arena.

IAPO members get reduced registration fees and opportunities for subsidies to attend. For further information please visit: www.globalpatientscongress.org



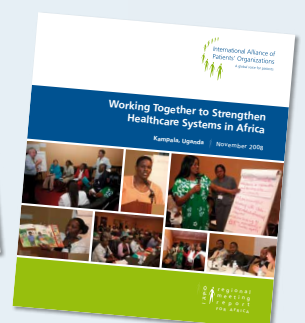
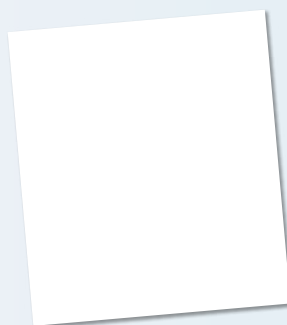
Thank you, and congratulations for putting together a really inspirational event that was not only well organised but also very enjoyable. I have to say I would expect nothing less from IAPO! I am looking forward to working on some of the ideas and initiatives that came out of the conference.
Thalassaemia International Federation, IAPO Member



Regional Strategy

IAPO recognises the importance of working not only at the global level but also at the regional level, in order to develop and strengthen the global patients' voice. Through advocacy and capacity building workshops, IAPO's Regional Meetings enable patient groups to identify strategies to overcome shared challenges and work together towards common aims.

To further our work to increase global participation in patient-centred healthcare, and build the capacity of patients' organizations around the world to be effective advocates, we have developed a Regional Strategy. Driven by members, the overall purpose of the Regional Strategy is to set in place a clear plan with tangible aims and goals that will guide IAPO's approach to activities in each world region. For further information on the Regional Strategy and upcoming projects please visit: www.patientsorganizations.org/regions



putting patients at the centre of healthcare

International Healthcare Policy

IAPO has Official Relations status with the World Health Organization (WHO) and engages with WHO and other international bodies on healthcare policy issues. We represent the patients' voice at official WHO meetings through interventions on relevant agenda items and meetings with stakeholders.

We facilitate IAPO member representatives to attend and to engage with WHO and provide information and training on working with WHO. In this strategic period, there will be more opportunities than ever before for our members to contribute to our international healthcare policy work and engage in international decision-making processes. We consult with members on policy issues to accurately represent the

global patients' voice in policy processes globally, according to our Policy Framework, and provide tools to enable members to disseminate those policy positions for their own purposes.



The IAPO event at the World Health Assembly (WHA) 2010 was very useful for me, as I became aware of the similarities in risk factors between Alzheimer's disease and other non-communicable diseases. It was good to meet with colleagues from other NGOs and I contacted several of them later in the year for an exchange of ideas.
Marc Wortmann, Executive Director, Alzheimer's Disease International, IAPO Member

Strategic Plan 2010–2014

IAPO's Strategic Plan for the period 2010–2014 provides a clear framework for policy activities on a wide range of healthcare issues that include, but are not limited to, chronic disease prevention and management, clinical trials, health literacy, patient information, and patient safety. We work with our members to achieve our strategic objectives and enable the engagement of patients in all decisions that affect their health and quality of life.



IAPO's Strategic Goal 2010–2014:

To strengthen the impact of the global patients' voice in decision-making processes globally.

IAPO is committed to achieving this goal in order to lead positive changes in healthcare design and delivery which ensure that the needs of patients globally are equitably and appropriately addressed, leading to beneficial health outcomes and improved quality of life.

We will do this through the following strategic objectives:

1. Engagement:

Patients' organizations will be better engaged in influencing decision-making at an international level.

2. Voice: The global patients' voice will be strengthened,

ensuring it accurately reflects the diverse needs and experiences of patients globally and is well communicated.

3. Member-led: Increased participation of IAPO member patient representatives in all aspects of IAPO's work, ensuring that the voice of patients globally will be integral to IAPO's work.

4. Sustainability: IAPO's capacity and sustainability as an organization will be developed in the most appropriate ways to ensure that IAPO can achieve its vision.

For information on how these objectives are being implemented, and to view IAPO's full Strategic Plan 2010–2014, please visit: www.patientsorganizations.org/strategicplan



The Public Personalities Against AIDS Trust (PPAAT) has benefited from the effective communication, coordination and networking mechanism among patients' organizations implemented by IAPO. PPAAT has participated in IAPO activities aimed at strengthening the capacity of patients' organizations, which has made it possible for PPAAT to effectively engage in national decision-making processes and participate effectively in the governance of the global HIV and AIDS response.

Tendayi Kateketa-Westerhof, Executive Director, Public Personalities Against AIDS Trust, Zimbabwe, IAPO Member



One of the benefits of being a member of IAPO is having a global voice and defence for access to better care for each patient regardless of nationality. IAPO has Official Relations with WHO and this gives us credibility in our own position when working nationally and regionally. As well as this, the technical support in areas such as patient-centred medicine and patient safety is crucial for organizations that haven't yet developed this level of advocacy.

Eva María Ruiz de Castilla, IAPO Governing Board Member and President, Esperantra, IAPO Member



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