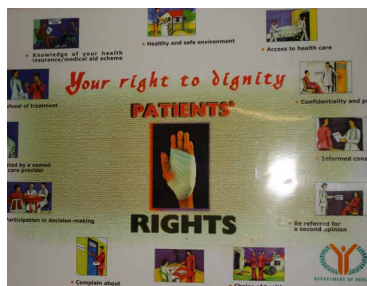
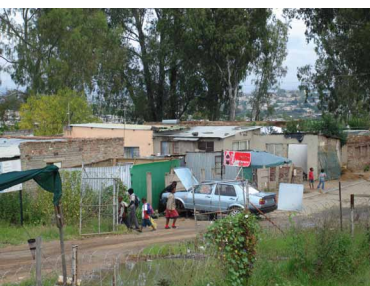
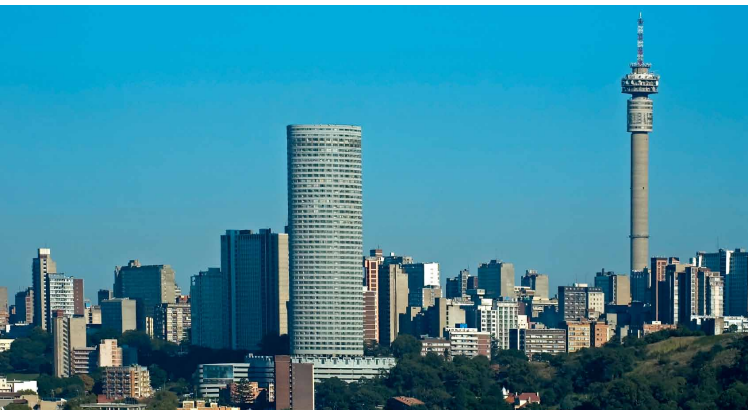


# Building a Regional Network of Patients' Organizations in Africa

Johannesburg, South Africa  18–20 April 2011





## **Organized by the International Alliance of Patients' Organizations**

### **With our thanks**

The IAPO Governing Board and staff team would like to thank everyone who gave their support to this event. In particular we would like to thank Zane Wilson, South African Depression and Anxiety Group (SADAG), and Vicki Pinkney-Atkinson, Patient Health Alliance of Nongovernment Organizations (PHANGO), who gave invaluable input and support to hosting these meetings. We would also like to thank and acknowledge the sponsors of the event, the Pharmaceutical Research and Manufacturers of America (PhRMA) and Eli Lilly. We would like to thank the IAPO members and all participants for their commitment, contributions and engagement in the event which enabled us to develop an action plan for our work in Africa, raise the patient voice and continue to build cross-sector alliances.

### **Meeting materials**

Presentations and agendas from the event are available online: [www.patientsorganizations.org/southafrica](http://www.patientsorganizations.org/southafrica)

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# Contents



Introduction	2
Working Together to Strengthen the Patient Voice in Africa	3
From Local to Global: the Role of Patient Groups in the Community	4
Partnerships and Collaboration: an African Regional Network of Patients' Organizations	6
Building Cross-Sector Partnerships to Meet Patients' Needs in Africa	10
Next Steps	13
IAPO Member Participants	13



# Introduction



In April 2011, the International Alliance of Patients' Organizations (IAPO) hosted a series of meetings in Johannesburg, South Africa. This event brought together 19 IAPO members from eight countries in Africa.<sup>1</sup> These groups represent patients with a wide range of health conditions including epilepsy, sickle cell, mental health, HIV/AIDS and autoimmune diseases. The objectives of the event were to: bring together IAPO members from across the region to develop an action plan for their work together as a regional network; raise the patient voice on key issues in Africa; and to continue to strengthen the contribution of the patient voice from the region in international healthcare policy.

The meetings were held between 18–20 April and included a local patient group meeting, an interactive workshop for IAPO members and a multi-stakeholder seminar entitled 'Building cross-sector partnerships to meet patients' needs in Africa'. The local patient group meeting brought together a diverse range of patients' organizations from across Johannesburg to strengthen networks in the city and surrounding areas and identify opportunities for their collaboration. In the IAPO member workshop, participants deepened their understanding of the shared healthcare challenges in Africa and engaged in discussion-based activities. In these discussions, they highlighted common priorities and identified opportunities for collaboration as a regional network of patients' organizations. The multi-stakeholder seminar brought together a wide range of healthcare stakeholders, including representatives from the World Health Organization (WHO) and the South African Department of Health, to share information and discuss the challenges of non-communicable diseases and safe medicines for patients and all healthcare stakeholders in Africa.

Throughout these events patient groups called for all healthcare stakeholders to work together to:

- Improve health literacy
- Increase patient engagement in decision-making
- Increase access to patient information
- Empower patients to make informed decisions regarding their healthcare

We look forward to our continued work together with colleagues in Africa to improve patient engagement in decision-making in order to strengthen healthcare systems by addressing patients' needs in Africa and globally.

*"When I get home I will hold a meeting with our staff and Board to sensitise them on this work. We will also follow up with the Ugandan network of patient groups. I must say thank you very much, this event was fabulous and a dream come true."*

**Ruth Nankanja Sempa, Sickle Cell Association of Uganda**

<sup>1</sup> Cameroon, Ghana, Malawi, Nigeria, South Africa, Uganda, Zambia and Zimbabwe.

# Working Together to Strengthen the Patient Voice in Africa



I would like to thank all IAPO members and participants who made this event a great success and demonstrated the value of coming together to find a common voice which can strengthen how we represent the constituents we serve. In November 2008, IAPO first came to Africa to hold events in Kampala, Uganda, to develop networks between patients' organizations in the region, build multi-stakeholder collaborations and strengthen the contributions of the African patient voice in international healthcare policy. Three years on and great achievements have been made: IAPO members in Africa have almost doubled and contributed to the global patient voice; they have engaged with their national ministries of health, the World Health Organization (WHO), the World Health Professions Alliance (WHPA) and other key healthcare stakeholders in the region and around the world; and they have been invited to speak at national, regional and international events.

The time had come to build on these successes and consolidate the work of IAPO members in Africa to strengthen our network and identify our common concerns and opportunities to work together. This event in South Africa was an important opportunity to discuss developments in the challenges we are facing in healthcare in Africa and establish our strategy for collaboration, by identifying a shared agenda through which we can collaborate with a strong unified voice. This work forms part of IAPO's Regional Strategy, which aims to increase global participation in patient-centred healthcare and build the capacity of patients' organizations around the world to be effective advocates for patient-centred healthcare. In Africa we are working towards this vision by building the capacity of our members to reach out to patient groups across the region and build a strong network that can advocate for patient-centred healthcare.

The healthcare challenges in Africa are complex and multifaceted: we face the double burden of communicable and non-communicable diseases, large inequities in the treatment and prevention of disease, and stigma and discrimination. These problems are compounded by widespread poverty, gender inequalities, socio-cultural issues and a lack of cooperation between sectors. I strongly believe that we can improve the lives of people in the region through the practice of patient-centred healthcare, and collaboration is an essential element in making this a reality. I refer here to my favoured Luganda proverb from Uganda, 'agali awamu, ge galuma ennyama', which means 'the teeth that are together are the ones that are able to bite the meat'. It is essential that we work *together* as patient advocates and healthcare stakeholders in Africa to strengthen the patient voice and achieve patient-centred healthcare here, as it is only through this approach that we can truly meet people's healthcare needs.

**Regina Namata Kamoga, IAPO Governing Board Member  
and Country Manager (Uganda), Community Health and Information Network (CHAIN)**





# From Local to Global: the Role of Patient Groups in the Community

## Local Patient Group Meeting, 18 April 2011

To maximise the opportunity to build patient group networks whilst in South Africa, IAPO, the Patient Health Alliance of Non-Governmental Organizations (PHANGO) and the South African Depression and Anxiety Group (SADAG) held a local patient group meeting at Morningside Medi-Clinic, Johannesburg, on 18 April 2011. This meeting was a valuable opportunity to share the work of IAPO as a global alliance of patients' organizations and the work of our local members, PHANGO and SADAG. The meeting brought together over 40 patient representatives from Johannesburg, representing a broad range of patient groups from small grassroots organizations working with patients at the local community level, to larger national organizations working to involve patients in decision-making at the national level. Participants represented patients with conditions that include cancer, diabetes, Alzheimer's, HIV/AIDS, malnutrition, mental health, leprosy, Parkinson's and multiple sclerosis. At the meeting participants had the opportunity to share their experiences and identify common challenges and objectives.



The meeting opened with short presentations from Regina Namata Kamoga, IAPO, Vicki Pinkney Atkinson, PHANGO and Cassey Chambers, SADAG, with introductions to these organizations and their work at the international, regional and national levels. In the plenaries, similarities between patient groups at all levels were highlighted. Also shared were many examples of how organizations can support each other through sharing experiences, resources and working together towards common objectives. As members of IAPO, PHANGO and SADAG described the way in which the patients they represent are represented at the global level through IAPO, as well as the important work that they do at the national and community levels to meet the needs of patients in South Africa.



The presentations were followed by a facilitated discussion in which participants actively engaged in discussions about their work and the challenges they face. Many of the groups attending provide essential services for vulnerable and disenfranchised patients in resource-poor settings yet struggle to gain funds to sustain their work. They spoke about the lack of support for their work and the need for training to enable them to professionalise and more effectively engage in their healthcare environments to ensure that the patient and community voice is heard. The need to

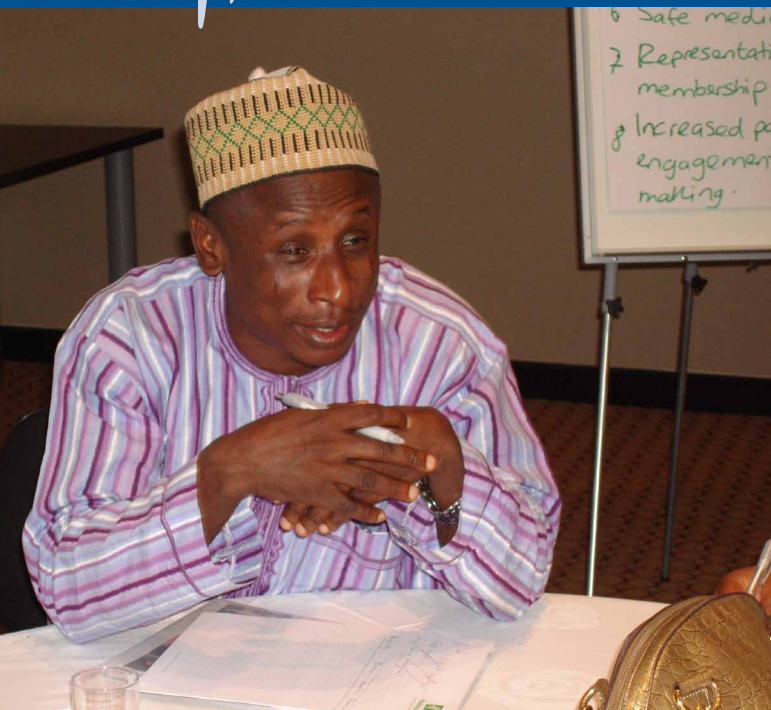


provide education for patients to enable them to understand and manage their conditions was also highlighted and patient groups called for more tools and resources in order to meet this need.

Although the remit of the participants' work is broad, they were able to identify common aims in their work and opportunities for joint learning. Funding, sustainability and education were issues raised by all participants at the meeting and they explored the similarities and variances in their challenges and how they might support each other. It was clear that the participants were working in difficult contexts and striving to meet the complex needs of patients in their communities. They highlighted the potential benefits of creating a local network which included having access to support and being able to share experiences and learning. PHANGO and SADAG expressed that the value of sharing and collaboration had been made evident at the meeting and committed to exploring how it might be possible to facilitate continued communications between the meeting participants. Recognition and support of the important role of these patient groups in the community will help to sustain their work, which provides an invaluable resource in their healthcare system.



# Partnerships and Collaboration: an African Regional Network of Patients' Organizations



## IAPO Member Workshop, 18–20 April 2011

On 18–20 April, IAPO members from the African region participated in a workshop to develop their capacity to work together as a regional network. The aims of the workshop were for members to deepen their understanding of the healthcare challenges in Africa, discuss the challenges of their work, highlight common concerns and identify objectives for IAPO's regional work in Africa.

IAPO members were welcomed to the event on 18 April in an informal reception in which they introduced their work and their expectations for the meeting. Their main expectations included the opportunity to learn more about the work of other IAPO members in Africa, build knowledge, find common aims and strengthen their network.

On 19 April the workshop began with a welcome from Jo Groves, IAPO's Chief Executive Officer (CEO), and Regina Namata Kamoga, IAPO Governing Board Member, who outlined that the event formed part of IAPO's Regional Strategy. This strategy aims to increase global participation in patient-centred healthcare and build the capacity of patients' organizations around the world to be effective advocates for patient-centred healthcare. This was followed by an overview of healthcare issues in Africa and the challenges which patients face due to inadequacies in healthcare systems and policies, lack of access to safe, quality and appropriate healthcare and information, and the double burden of communicable and non-communicable diseases.

*"I really appreciated and learned from other members' experiences."*

**Christian Locka, Action for Humane Hospitals, Cameroon**

In the discussion group activity which followed, members discussed the challenges they face in their work, which included a lack of technical support and current data, stigma and discrimination, lack of recognition for the expertise of patients, lack of trust to share information, and a shortage of patient information in the community. Eva Maria Ruiz de Castilla, IAPO Governing Board Member and President of Esperantra, Peru, facilitated the discussion. Eva Maria highlighted that patients' organizations in Latin America and in all developing regions are





facing comparable challenges and there is a need to work together to address these challenges. Through further discussion the common concerns of participants emerged as:

- Stigma and discrimination
- Wider recognition of all chronic conditions
- Health information
- Health literacy
- Political commitment to patient involvement
- Safe medicines
- Representative IAPO membership in Africa
- Patient engagement in decision-making



*“As participants we were all involved, and this is empowering and also leads to a rich exchange of information and knowledge.”*

**Robinah Kaitiritimba, Uganda National Health Consumers/Users’ Organisation (UNHCO)**



The patient group leaders reflected on how their organizations address these challenges. For example, the Sickle Cell Association of Uganda demonstrated their expertise in advocating for involvement at the Ugandan Ministry of Health, which has gained them a place on the non-communicable disease technical committee of the Ministry of Health. Becoming a partner in cross-sector projects and providing expertise can begin to address the need for patient involvement in healthcare decision-making and build its acceptance. The participants highlighted the need for collaboration between all healthcare stakeholders to address these issues. The multi-stakeholder seminar which followed that afternoon provided an opportunity to ask questions regarding patient involvement with a range of healthcare stakeholders and continue the morning’s discussions in a wider forum.

*“In the group sessions members shared a lot of information showing that we do have common challenges. The presentation on the Ugandan network demonstrated that it can be used as a model in other countries.”*

**Nana Yaa Agyema, Sharecare Ghana**

The member workshop resumed on 20 April, with a reflection from members on discussions from the day before, advocacy and social media sessions, and activities to identify priorities and actions plans for working together as a regional network. A case study was presented by Ruth Nankanja Sempa, Sickie Cell Association of Uganda, and Dickson Ndyahika, Epilepsy Support Association, on their work as part of a network of IAPO members in Uganda. Ruth and Dickson outlined the aims of the network to advocate for patient-centred healthcare in Uganda. They have undertaken tireless advocacy and media activities in order to establish a dialogue with their Ministry of Health and the strength of working as an alliance of patient groups helps them to raise awareness of certain issues such as non-communicable diseases. The network share knowledge and experience and identify shared issues, which helps them to campaign more effectively.



This case study highlighted that to gain partnership with governments and healthcare stakeholders some of the attributes they look for are:

- Representation of a large constituency
- Membership of national, regional and/or international alliances
- International affiliations and meeting attendance
- Demonstration of the contribution you bring, e.g. knowledge and information



“ The network share knowledge and experience and identify shared issues, which helps them to campaign more effectively. ”

With advocacy needs identified, participants considered how media and communications can support this work in a session on social media which included a presentation on popular social media tools and a discussion on how they might be used. Awareness campaigns can be achieved through social media as well as local and national media, and participants recognised the need to engage with the media and wider populations to increase coverage of their advocacy work. This can be achieved by sending articles to the media, inviting them to events and by posting information online.

In the final session of the workshop, participants reflected on the common challenges identified the day before and identified priorities for their work together as a regional network. Participants worked in groups to develop action plans based on the priorities they had identified, outlining objectives and activities. Participants then considered how these action plans could be consolidated in order to establish objectives for the network which include:

- Communicate a strong, unified voice from IAPO members in Africa
- Establish regular communications between the IAPO African Regional Network to include the sharing of information and resources
- Improve patient-provider relationships through demonstrating the need for patient-centred healthcare
- Increase access to patient information
- Build cross-sector alliances with all healthcare stakeholders
- Increase and diversify IAPO membership in Africa

Participants shared ideas for activities which they could undertake to achieve these objectives and how they can use existing resources and materials in order to establish sustainable activities. Such materials include IAPO's toolkits, policy statements, Declaration on Patient-Centred Healthcare and online forums. The need to ensure that activities are culturally and nationally relevant was discussed; raising the importance of engaging community leaders in educational campaigns and ensuring that national protocols are considered in advocacy activities. Participants then recorded their first activity to undertake when they returned home, which included sharing information with a Ministry of Health, disseminating the outcomes of the meeting with members of their network, contacting all members that attended the meeting and informing the media about the meeting.



Regina Namata Kamoga closed the workshop with thanks to everyone and highlighted the value of the breadth of experience and information which IAPO members have and how the patient voice in the region can be strengthened through their collective work.

*"It was a wonderful discussion forum with a lot of information gained."*

**Anthonia Onwufuju Oladapo, Association of Women Living with HIV/AIDS in Nigeria**



# Building Cross-Sector Partnerships to Meet Patients' Needs in Africa



## IAPO Seminar, 19 April 2011

Patients' needs in Africa will only be met if there are effective cross-sector partnerships between healthcare stakeholders. To stimulate information exchange and dialogue, IAPO convened a seminar with a range of stakeholders from across the healthcare system in Africa, including: patient groups, medical professionals, policy-makers, healthcare industry and media representation, and representatives from the Department of Health in South Africa and the World Health Organization. The seminar comprised of two panel sessions, each addressing a major challenge to health in Africa: the prevention and control of non-communicable diseases and access to safe medicines.

### Panel 1: Non-communicable diseases

Non-communicable diseases (NCDs) are having an increasingly negative impact on the health and socio-economic development of people throughout the region, further complicating the existing health challenges facing Africa. With the United Nations Summit on Non-communicable Diseases in September 2011, this panel session was an opportunity to review the situation in Africa and consider patient needs and strategies to prevent and tackle non-communicable diseases in the region. Four speakers shared their perspectives and information on their work to address non-communicable diseases.

Sandhya Singh, Director, Directorate Chronic Diseases, Disabilities and Geriatrics, Department of Health, South Africa, stated that there was a need to move towards a sustainable approach to chronic disease prevention and management. A core part of this work involves delivering a joined up service and supporting and empowering poor communities to look after themselves. She highlighted that the best outcomes will be achieved only when the Department of Health is working with industry and with civil society. Dr Ratna Devi, Chief Executive, Chronic Care Foundation, India, gave a remote film presentation on their initiatives to reach the population in remote parts of India.

Eva Maria Ruiz de Castilla, IAPO Governing Board Member, gave a global overview of the current initiatives to address non-communicable diseases, with particular focus on the role of civil society organizations in the lead-up to the UN Summit in September 2011. Nana Yaa Aygeman, Coordinator of Sharecare Ghana, who has a rare autoimmune condition, shared her experience of a healthcare system that does not understand rare conditions and the detrimental impact this has had on her health. She stated: *"Patients suffer the consequences when diseases are not understood or seen as a priority, impacting on funding for education, diagnosis and treatment, and dismissive treatment of patients."*



All speakers highlighted that all stakeholders have a role to play in bringing about better health outcomes for patients. However, the success of meeting these challenges depends on the active empowerment and involvement of the communities affected.

The discussion highlighted the competition for funding and services between disease areas and the need for all patients to receive high-quality, equitable healthcare. The burden of NCDs is predicted to rise sharply, with the greatest increases in the poorest regions of the world, and political leaders and key stakeholders must meet their commitments and renew their efforts to address this threat. Patient advocates called for greater involvement in the design and delivery of strategies to prevent and manage non-communicable diseases and chronic diseases more broadly. Regina Namata Kamoga, IAPO Governing Board Member, stated: *"Patients' organizations need to be recognised in official relationships with the World Health Organization on a national, regional and international level and with national Ministries of Health, as they are a vital partner in realising success in the design, delivery and implementation of healthcare policies."*

*"The NCDs session was most interesting and useful; this is because we have always worked on NCDs but with no recognition of that area of work."*

**Bisi Bright, LiveWell Initiative, Nigeria**



## **Panel 2: Safe medicines**

The second panel session focused on the issue of safe medicines. Patient safety in general, and safe medicines in particular, is a global issue and one that has its own particular challenges in Africa, which include leaky supply chains, high cost of medicines, low literacy levels, significant under-reporting and failure to complete the course of treatment. Two issues of relevance to patients were discussed: the safe use of medicines and the prevalence of counterfeit medicines in Africa, which are both of critical concern to patients and the entire healthcare sector.

Scott LaGanga, Executive Director, Partnership for Safe Medicines, gave an overview of safe medicines issues, highlighting the global situation and sharing information on both global initiatives and those focused on Africa which seek to address the proliferation of counterfeit medicines. Bisi Bright, Consultant Clinical Pharmacist and Public Health Manager, and 1st Chairman and CEO, LiveWell Initiative, Nigeria, shared her experience with the safe use of medicines and counterfeit medicines as a pharmacist in Nigeria. Bisi stressed that governments, health professionals

and drug regulators all have a role in ensuring patients receive safe medicines and know how to take them correctly and safely. She highlighted that empowered and informed patients and partnerships between health professionals and patients are essential tools for improving the safe use of medicines in Africa.



Elizabeth Matare, Chief Executive Officer, South African Anxiety and Depression Group, highlighted the problems regarding safe use of medicines in Sub Saharan Africa which are compounded by low literacy levels. Elizabeth shared an innovative communications tool: a 'speaking book', which shares information through an audio recording along with pictures in a book to enable people that cannot read to still be able to learn about their condition and the safe use of medicines.



Patient representatives agreed that they could take a stronger role in addressing the issue of safe medicines through advocacy and educational initiatives in partnership with other patient groups and other stakeholders in the region. There was recognition of the challenges to delivering equitable and appropriate healthcare and the role of patients' organizations as a vital stakeholder in policy-making.

*"Patient safety is the responsibility of governments, service providers, patient groups and all those involved in the healthcare delivery system. By sharing the work we do, especially best practices, we can create effective collaborations to address such issues."*  
**Edward Ogenyi, Network of People Living with HIV/AIDS in Nigeria**

# Next Steps



This event was IAPO's second regional event in Africa and provided a valuable opportunity to reflect on the successes of IAPO members, share experiences and identify the opportunities for work together in the future. Following the event, IAPO staff have worked with members in Africa to consolidate the objectives and action plans developed at the meeting and begin work as a regional network. A steering committee will be created to identify activities for the network, share materials and lead the implementation of the action plan to achieve the objectives identified at the meeting. Members aim to improve health literacy and empower patients in the region, to increase access to patient information on safe medicines and to increase patient engagement in policy-making.

IAPO continues to work on a vision to increase global participation in patient-centred healthcare and build the capacity of patients' organizations to be effective advocates for patient-centred healthcare. In Africa we are working towards this vision by building the capacity of our members to reach out to patient groups across the region and build a strong network that can advocate for patient-centred healthcare in cross-sector alliances. The strategy for Africa is driven by IAPO members in the region and their contributions are essential in meeting the context-specific needs of the region. IAPO will provide services to support members' activities on a national level and a forum of exchange to continue to share initiatives and experiences.

*"When I return home I plan to mobilise patient groups and share information with my Ministry of Health."*

**Ellos Lodzeni, Patient Welfare Foundation, Malawi**

*"My first activity after the event will be to engage with members and send them feedback about the African regional strategy."*

**Nancy Okecha, Joyce Fertility Support Centre, Uganda**

## IAPO Member Participants

### Cameroon

- Action for Humane Hospitals, Cameroon

### Ghana

- Sharecare Ghana

### Malawi

- Patient and Community Welfare Foundation

### Nigeria

- Association of Women Living with HIV/AIDS in Nigeria
- Diabetic Association of Adamawa

- LiveWell Initiative

- Network of People Living with HIV/AIDS in Nigeria

- Positive Life Association of Nigeria

### South Africa

- Diabetes South Africa
- Patient Health Alliance of NGOs in South Africa
- South African Depression and Anxiety Group

### Uganda

- Community Health and Information Network
- Epilepsy Support Association Uganda

- Joyce Fertility Support Centre Uganda

- National Care Centre

- Sickle Cell Association of Uganda

- Uganda National Health Consumers/Users' Organisation

### Zambia

- Bethesda Zambia

### Zimbabwe

- Public Personalities Against AIDS Trust

For more on IAPO membership, please visit:  
[www.patientsorganizations.org/membership](http://www.patientsorganizations.org/membership)



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