# Action on Non-Communicable Diseases Will Fail Without the Involvement of Patients

Langue Anglais

April 21, 2011 Patient advocates have called for greater involvement in the design and delivery of strategies to prevent and manage non-communicable diseases (NCDs), and chronic diseases, at the International Alliance of Patients' Organizations (IAPO) African Regional Network Meeting in Johannesburg, South Africa. The meeting was held with the support of two South African patient groups: the South African Depression and Anxiety Group (SADAG) and the Patients' Health Alliance of NGOs (PHANGO). It is urgent that effective strategies are put in place to protect people from the threat of chronic disease to their health and quality of life.

There are many challenges to improving healthcare for people in Africa and efforts have been met with varying degrees of success. In 2011, there is an important opportunity for political leaders and key stakeholders to renew their commitment and efforts to meet the ever-growing threat of NCDs to the social and economic development of people in Africa.

The burden of NCDs is predicted to rise sharply with the greatest increases in the poorest regions of the world. Bringing together 18 patient groups from nine African countries: Cameroon, Ghana, Liberia, Malawi, Nigeria, South Africa, Uganda, Zambia and Zimbabwe, the meeting participants shared challenges and solutions to overcome them whilst committing to working in partnership with all stakeholders.

In a seminar entitled, 'Building cross-sector partnerships to meet patients' needs', patients were joined by representatives from the Department of Health in South Africa, the WHO and the health professions amongst others. The discussion was open, with recognition of the many challenges to delivering equitable and appropriate healthcare and the role of patients' organizations as a vital stakeholder in policy-making. Participants expressed frustration that health policies and initiatives rarely include patient involvement. They felt that their expertise as the person living with a condition was rarely taken into account and yet, those with chronic conditions know best how they affect their lives. They can help ensure healthcare services are developed to make the most efficient and appropriate use of limited resources.

In addition, they raised concerns about the inequity of provision of funding and services between chronic conditions which leads to competition between disease areas rather than treating all patients whether they have a common and well known condition, such as cancer, or a rare disease. Nana Yaa Aygeman, Coordinator of Sharecare Ghana, who

has a rare autoimmune condition, shared her experience, she said, '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'.

Highlighting the need for official recognition of patients' organizations to be full and equal partners in decision-making processes, Regina Namata Kamoga, IAPO Governing Board Member and Country Manager (Uganda), 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'.

IAPO member patient groups in Africa are positive about taking forward work with these groups and the potential they have together to effectively advocate to strengthen healthcare systems ensuring they better address patients' needs in Africa. Note to Editors: About IAPO: IAPO is the only global alliance representing patients of all nationalities across all disease areas and promoting patient-centred healthcare worldwide.

Our members are patients' organizations working at the local, national, regional and international levels to represent and support patients, their families and carers. IAPO has over 200 members which span over 50 countries and 50 disease areas and through membership represents an estimated 365 million patients worldwide. For further information, please contact: Mr Jeremiah Mwangi, Policy & External Affairs Director, IAPO T: +44(0)20-7953-7613; Email: jeremiah@patientsorganizations.org [1] Website: http://www.patientsorganizations.org [2]

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