

Good morning and welcome! I hope you had a good travel.

I would like to say you that we are here from 32 different Countries. It's really a pleasure and a honor for me, as new Director of Active Citizenship Network, host representatives of patient and civic associations, health care professionals, Institutions, companies not only from the European Union but also, for example, Kosovo and Ukraine as well as experts coming from USA and India.

All together to discuss the important topic of empowerment in chronic disease.

Thank you every one to be here

So, why an European Patients Rights Day? If for most of us it is a fix appointment, for others it is the first time and so it is important to say some words on its meaning:

In 2002 Active Citizenship Network, in collaboration with 12 citizens' organizations from different EU countries, drafted The European Charter of Patients' Rights (I hope you have received it), that states 14 patients' rights that together aim to guarantee a "high level of human health protection" and to assure the high quality of services provided by the various national health services in Europe. The reinforcement of these rights will become effective only with the cooperation and commitment of all healthcare stakeholders in every EU country. It is thus essential to increase awareness regarding the importance of patients' rights and everyone's responsibilities in guaranteeing their respect. We believe that celebrating a European Patients' Rights Day every year in all the EU Member States would greatly contribute to this goal. It is a common occasion to inform, discuss and take commitments to improve patients' rights in Europe and in each member state. For this reason ACN, together with citizens' and patients' organizations throughout Europe, have taken the initiative to organize for the last five consecutive years the European Patients' Rights Day. celebrated through local, national and EU events all over Europe: last 17 of April, for example, I went in Maastricht to celebrate it in the Netherlands.

Well, this year the objective of the conference is to try to clarify the concept of patient empowerment, sharing best-practices on the added-value of citizens' organisations in this empowerment, not only intended as self-management of chronic diseases, but also as patients' participation in health decision-making.

The key role of citizens' organisations in the empowerment of individual patients with chronic diseases and their families is often underestimated. Patients with chronic diseases do not only have to cope with the medical aspects of their condition, but also with the caring, social, relational and psychological aspects of their disease, which often have as much weight as the disease itself on the quality of their lives.

The added-value of citizens' organisations consists in a global approach to patient empowerment, supporting, informing educating and training patients to help them face the many difficulties of their daily lives. This global approach is necessary to make patients strong enough to collaborate with their health care professionals on an equal footing, helping them personalize the plan of care, participating actively in the management of their disease, and using health services more effectively.

We are conscious that there is a general concern about the increased costs that shall derive from the pressure exercised by associations of patient with chronic diseases on health institutions, because their main objective is supposed to be increased access to and better reimbursement of innovative and expensive treatments and drugs.

But, at the same time, they play a decisive role in the development of a modern patient-centred health system.

Therefore, we believe **the empowerment of patient organizations should be considered as an added value**, because they become actual partners in the health policy, sharing with the institutions the responsibility of finding the best balance between the interest of patients and the sustainability of the system. This shall be achieved through the creation of networks and alliances, which allow the identification of common objectives and goals. This includes the development of a global and long-term perspective, which goes beyond the single chronic diseases and reflects the general interest of patients.

Patient empowerment does therefore have two different but complementary dimensions:

1. Improvement of a person's capabilities to effectively self-manage his/her chronic disease;
2. Enhancement of patient groups' capacities to participate efficiently in health policies.

In both cases, citizens' organisations – which include self-help groups, associations of patients with a chronic disease, networks and umbrella organisations - play an essential role.

The first goal of the day, as I said before, is to increase awareness and information on the concept of patient empowerment. To do it, with the participation of all of you, we gathered (please see the report you can find on your desk) 26 best practices of different citizens and patients' organisations, coming from a wide range of EU countries. And some of them will be presented in the afternoon. We'll also host the intervention of the Dg Sanco and two representative of two fundamental health professionals to clarify which is their point of view and experience on patient empowerment.

The second goal is to try to demonstrate that empowered patients with chronic diseases and their organisations are a resource and not a cost. For this reason we would like to compare the different models of networks both at national and EU levels and analyse their respective structures, ways to work and the main results (how they engage a wide scope of organisations, overcoming their differences and potential conflicts; identify and efficiently voice the common interests of patients in the health policy-making; empower local & national patient organisations etc..).

The third objective of the day is to reach an agreement on a shared MANIFESTO FOR THE EMPOWERMENT from the civic association point of view (addressed to the new Member of European Parliament and in general to the European Institutions) about the importance of empowerment of chronic patients and their associations, and how this could be better taken into account in the framework of the EU reflection process on chronic diseases. The manifesto should be subscribed by all the organizations involved in the conference and sent to the new Member of European Parliament. We will discuss it during the afternoon.

During the second day we would like to realize a focus talking about "The role of patient organizations in promoting and supporting life changing and life-saving research into treatments or cures for chronic diseases".

The panel and discussion will consider the importance of engaging the patient voice in the formulation and support of national and international policies that promote pharmaceutical and other medical research that leads to new preventions, treatments and cures for chronic diseases for which there are few, if any adequate treatments and cures.

So it is a pleasure to give the floor to all the speakers after me.

Thanks you again wishing for a useful and interesting conference.