



The Coalition of Patient Organizations with Chronic Diseases

Zagreb, October 29 2013



About COPAC



The Coalition of Patients Organizations with Chronic Diseases in Romania is registered since 2008.

COPAC mission is to empower/support patients and patients' organizations to act in unity and efficiently for the protection and promotion of patients' rights.

COPAC will sustain the importance of authorities real consulting of the patients regarding the changes made in the healthcare system, so that the patients will properly be represented in all the patient decision commissions at the local and national level. This action is ment to make the patients right's to be known and respected in Romania.



Members of COPAC



COPAC gathers presently 13 members, legal entities exclusively, representing patients' organizations covering a wide range of pathologies.

- The National Union of People infected with HIV/AIDS Organizations
- Multiple Sclerosis Society in Romania
- The Romanian Transplant Association
- The Romanian Alliance of Rare Diseases
- The Romanian Associations of Hemophilia
- The Black-Sea Baylor Foundation
- The Romanian Association of People with Major Thalassaemia
- The Antiparkinson Association
- The Association for the Tuberculosis Patients' Support
- The Rare Cancers Romanian Association
- The Prader Willi Association
- Romanian Oncology Patients Association
- Patients Association with Inflammatory Rheumatic Disease



Goals



Goal 1 - Ensure a patient perspective is integrated in the formulation, implementation, and monitoring of national and EU health policies

Goal 2 - Defend and promote patients' rights and equal access to quality information and services for all Romanian patients

Goal 3 - Develop professional, inclusive and representative patients' organizations in Romania

Goal 4 - Ensure COPAC sustainable development as a representative platform of patients' organizations (internal focused strategic goal)



Context



The last few years have been difficult for the Romanian patients. The amount of new information provided to them made the role of the patient associations very important.

There have always been questions about access to treatment of patients, ensuring quality and equity of care, financial resources for healthcare, protection of data / patient rights.

The associations are passing through rough times, being in the position of sustaining the patients' rights. The health system in Romania is within continuous restructuring process (in themes of institutional structure and legislative policy provisions). That is the reason because Romanian patients association tried to get help from umbrella organization from European Union, like European Patients Forum (COPAC is a member of EPF since 2010).



Activities



- The National Forum of Patients Organizations, where we had public debates on different policy issues (key issues: equal access to treatment and medical services for patients, social protection, etc.).
- European Patients' Rights Day, organized as a round table where we focused on the promotion and protection of patients' right.
- Participate at national debate where we facilitate the dialogue among stakeholders and organizations of patients.
- Over twenty debates (only this year) at local level with the participation of the local authorities and local patients organizations.
- We started a info help line for the patients, and we try to educate and inform the patients about their rights
- National Catalog of Patients Organizations.



EPF Membership



What to do?

In order to achieve the objectives of the organization, we realized that we need a Strategic Plan. Planning is linked to the organization's success, which is why organizations that have a planning systems are more successful and help them to define their goals and tasks.

Who can help us?

Based on this idea and having a solid partnership with European Patients' Forum, we were very happy by their initiative to implement the Capacity Building Program in Romania, and of course the organizations members of COPAC have expressed interest in benefitting from external expertise in defining the strategy and actions for the next years.



Results



After we completed the Strategic Plan we could evaluate some key points that emerged from the planning, key points that helped us in changing the future strategy of the organization:

- We managed to find our strengths and weaknesses;
- To see where we need help and where we can provide help;
- To know how to streamline the workings of the organization;
- To improve the working with member organizations;
- To increase visibility of the organization;
- To improve communication between organizations;
- To have a vision;



Vision



A world with a powerful and influential patients' movement, where health and social systems are based on the real needs of patients

