

All-Ukrainian Council for patients rights and safety	Association of medical workers	All-Ukrainian Association of palliative care
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REPORT

On activities of abovementioned NGOs in Palliative care development in Ukraine (2006 – November 2007)

Accordingly to the WHO statement (2002), palliative care – this is approach which aims to maximize the life quality of patients and their families facing the problem of the incurable illness. Looking at palliative care as one of the forms of the assistance to people, our organisation, with the support of different partners, among them, International Renaissance Foundation (IRF), made such activities.

Studying of the situation with the palliative care development in Ukraine

- The basic information on hospices, palliative care units etc was collected. The leading ukrainian experts on palliative care were found, among them – Alexey Datschenko, Svitlana Martyniuk-Gres, Lydmila Andriishyn, Ludmila Buslawa, Walerij Khmarsky, Witaly Ekzarkhow, Wiktor Paramonow, Wktor Pologow etc.
- The foreing experience of palliative care was studied.
- The analysis of legal base for palliative care was done.
- The palliative care implementation into Ukraine was substantiated.

Collaboration with the Ministry of Health, Ministry of social affairs and other authorities. Changing of the legislative base about palliative care

- On initiative of the All-Ukrainian Council for patients rights and safety and with the support of Ministry of Health, Ministry of social affairs the Order of MOH (# 201, issued on July 6, 2006) about the creating of the Interdisciplinary Task Force on palliative care. President of the Council for patients rights Prof. Y.Gubsky is the Co-Chairman of the Task Force. The Group unites representatives of the Ministry of Health, Ministry of Social Affairs, and Association of medical workers and Association of palliative care, All-Ukrainian Network of People LWHA, different Churches and individual experts. Actually, the Group consists of 30 Ukrainian and foreing experts. Thus public society was included to the process of solving actual health care problems. In this process, the main goal is ensuring of health care where a patient is in a center.
- In Kharkiw, with the active participation of the Interdisciplinary Task Force, the City Working Group on palliative care was formed. Vice-President of the Council for patients rights and safety Dr. Wiktor Serdiuk is the Deputy to the Chairman of the Group. Forming of the Group and starting of the development of this project is the unique experience for Ukraine, since city council had allocated such a great sum of 600.000 \$ for the development of this kind of services for the first time in Ukraine.
- In Cherkassy, with participation of experts of All-Ukrainian Association of palliative care the Coordination Cometee on palliative care development and elaboration of Conception of PC development in Cherkassy was created (Order of town council # 476, issued on May 16, 2007).
- In Luhansk, on iniciative of workers of All-Ukrainian Council for patients rights and safety and All-Ukrainian Association of palliative care in October 2007 the iniciative group on palliative care development was created. The group unites medica, social workers, journalists, clergy – from both governmental and non-governmental organizations.
- The group of Ukrainian experts and representative of the MOH participated with the support of IRF in the working visit to Moldova and Romania, which was organised by Association of medical workers in the frameworks of the East-East Program (International Renaissance Foundation). The goal of the visit is the

experience exchange in palliative care. During the visit, the meetings with workers of hospices, local administrative, leading representatives of European Association of Palliative care, associations of palliative care of Romania and Moldova were done. These meetings influenced creation of the Draft Strategy and Conception of palliative care development in Ukraine accordingly to international standards.

- With the support of International Renaissance Foundation the recommendations and guidelines about necessity of legal changes were done. Also, to this members of the Task Force contributed. They discussed the projects of documents which regulate activities of hospices and their staff. The projects of papers were proposed to Ministry of Health for consultation.
- Leading experts of the All-Ukrainian Council for patients rights and safety, All-Ukrainian Association of palliative care Mrs. Martyniuk-Gres, Mr. Alexey Datschenko, Mr. Oleg Bobrow the schemes of access to adequate opioids in Ukraine, alongwith the recommendation how to solve these barriers were created. Experts of the Council provided the expert evaluation of the barriers of medical usage of opioids and psychotropic substances; the draft changes to the actual legal base was proposed to Ukrainian Government and Cabinet of Ministries.
- On September 14-15, 2007 on initiative of All-Ukrainian Council for patients rights and safety the International conference on medical law and palliative care was held with participation of experts from France and Poland. One of the main results is agreement between Ukrainian and French sides about cooperation on improvement of Ukrainian legal base about pain control.
- After the public discussion the Project of the Conception of palliative care development in Ukraine aroused (with the support of IRF). Project of the Conception as well as other materials were proposed to the attention of the leading experts in Ministry of health and other organisations. The draft of Palliative care development Strategy in Ukraine was created. These documents are in the process of preparing them to attention of leading experts of Ministry of Health, Ministry of Social Labour etc.
- In the collaboration with the representatives of Ukrainian Orthodox Church the Draft Paper on spiritual care in palliative care was created.
- In the collaboration with the greatest religious confessions of Ukraine, Federation of protestant Churches of France and other religious communities about the implementing of chaplaince in palliative care and generally in medical system in Ukraine.
- Experts of All-Ukrainian Association of palliative care actively participated in the Task Force on social standards in palliative care development. The result of the work was creating of the Draft document which coordinates with other papers developed with support of IRF.
- The expert (consultations) support to local administrations in palliative care development was proposed in Kharkiw, Lwiw, Cherkassy, Luhans and Sevastopil.
- The needs assessment was done through all Ukraine by international expert on palliative care Marie Coughlan. This would great advocacy tool for support of development of palliative care in our country.

Organizational events

- Several meetings of the Palliative care Interdisciplinary Task Force were done with the support of IRF. Different questions were discussed then, mostly, about the coordination of activities in palliative care and forming of new palliative care staff. In the meetings about 70 experts from all parts of Ukraine participated. As one of the results, the Typical Status of a hospice was developed which is now is given to Ministry of Health for editing. Thus, the resultative and transparent dialogue between public society and state in questions of implementation of policy in health care was continued.
- The collaboration with organisations which help PLWHA was began. Aim of cooperation: experience exchange and coordination of efforts in establishing new and better medical and social care in Ukraine. The collaboration with regional AIDS centers began.
- 4 September 2006 the working meeting with the representatives of different denominations active in Ukraine (Orthodox Church, Greek-Catholic Church, Roman-Catholic Church, Baptists Church, Lutheran Church etc) were done. The directions of the possible cooperation in palliative care were discussed. The result of the meeting was that the special prayers for those who needs palliative care in many parish churches of Ukraine were organised.
- Our organisations participated in Public hearings in Ukrainian Parliament about the patients which suffer from cancer.
- Experts of All-Ukrainian Council and All-Ukrainian Association of palliative care are active members of the consultative council of the Health care Comeetee in Ukrainian Parliament.

- The campaign about the drawing of public attention to the problem of the palliative care was started. The cooperation with numerous mass-media from different regions of Ukraine and other countries was established. Publications about successes of palliative care in Ukraine are on the web-page of European Association of palliative care and other web-resources.
- In October-November 2007 with support of Open Society Institute and IRF the educational campaign dedicated to the World Hospice and Palliative care Day was launched. In 10 cities of Ukraine broad and numerous activities were organized. Their aim was to advocate palliative care and humanization of society.

Educational events

- Expert of All-Ukrainian Association of palliative care Alexander Wolf participated in the educational study visits to Poland and Slovak Republic. 9 hospices were visited.
- Experts of the Association of palliative care participated in the Scientific Conference “Challenges for civic care in 20 century” (in Bydgoszcz, Poland).
- 12 – 18 November representatives of the All-Ukrainian Council for patients rights participated in the OMI-OSI seminar “Palliative care in Geriatrics” in Salzburg (Austria). The event was organised by Open Society Institute (OSI), USA.
- Representatives of the Association of palliative care participated in the scientific seminar “International course of pain treatment”, in Poland.
- In December the study visit of our organisations representatives was organised to Romania and Moldova. The goal of the visit: studying of the practical experience of foreign colleagues in palliative care.
 - The project of training course “Multidisciplinary team work in palliative care system” was created. With was done with leading professors of the Institute of Gerontology of Ukraine and other educational facilities.
 - In the framework of the projects which are realised by Association of medical workers, agreements on cooperation between Wroclaw medical academy, Wroclaw palliative care society, Lodz medical academy, Lodz Hospice society, and All-Ukrainian Association of palliative care and Educational palliative care center, State educational geriatrics center etc was developed.
- Active participants of these programs will have an opportunity to be after the further trainings trainers themselves.

Development of the international cooperation

For development of the palliative care accordingly to international standards, the collaboration and information exchange with leading palliative care centers / experts is made. Among them:

- **European and International Associations of palliative care.** They support All-Ukrainian Association in its joining to these organisations. This, in its turn, will contribute to the presentation and lobbying of the palliative care in Ukraine.
- **World Health Organization.** Contacts with leading expert on opioids - Maria Cecilia Sepulveda Bermedo, who regards the possibility of providing of the expert support to Ukraine in this issue.
- **UK.** Association of palliative care, All-Ukrainian Council got kind consultative assistance from the organisation Hospice Information. Volunteer of the Association had numerous meetings with representatives of the hospices, during which she studied peculiarities of the planning and building of stationary hospices.
- **USA.** Representatives of the Council together with the All-Ukrainian Association of palliative care outlined principles of the cooperation with Open Society Institute (New-York).
- **Poland.** In 2006-2007 2 projects on palliative care education are realised. The education would be provided by specialists of Lodz and Wroclaw Societies of palliative care. In the projects, educating of ukrainian workers in Poland is foreseen as well as working meetings, round tables, simposia, and training seminars in Kyiv, Odessa, Lwiw, Iwano-Frankiwnsk, Sevastopol.
- Moreover, numerous contacts with leading experts on access to opioids and palliative care in general are made. These experts work in Canada, Albania, Kazahstan, Australia, France, Italy, Slovak Republic, Hungary, Moldova, Romania, Russia, Bulgaria, Serbia, Macedonia etc.

Projects, supported by the International Renaissance Foundation

Title of the project	Organisation which realised the project	What was realised in the frameworks of the project
Social Innovations in Palliative Care: Experience Exchange Between Moldova, Romania, and Ukraine	Association of medical workers	Analysis of the legal base on palliative care. Study visit to Moldova and Romania, meetings with palliative care experts from European, Roman and Moldova palliative care associations. During the visit, ways of engaging of public society and local administration representatives to the forming of national and regional palliative care programs were studied and discussed.
Public assistance with the development of palliative care in Ukraine through development of regional programs of palliative care providing and creation of the project Governmental Conception of Palliative Care in Ukraine	All-Ukrainian Council for patients rights and safety	During the realisation of the project the situation evaluation about the palliative care was done. The substantiation of palliative care was done. The international experience of palliative care providing was done. The public discussion of the State Conception of palliative care development was done. The project of the Conception, after the discussion together with both national and international experts was proposed to organs of the executive and legislative power.
Creation of the mechanism of cooperation between the society, government and Supreme Council of Ukraine on forming governmental policy on drug circulation and HIV/AIDS counteraction	All-Ukrainian Council for patients rights and safety	Providing of the barriers evaluation of the access to opioids for Ukrainian patients. The report on barriers and recommendations on their overcoming was proposed to responsible bodies.
Transborder cooperation in the implementation of the palliative care in Eastern Europe	Association of medical workers	The realisation of the project encourages improvements in the Draft Statute for Hospice Care and the Standards of Palliative Care in Ukraine; enables the partner relations and experience exchange between the experts in Poland and Ukraine. Thanks to the project, experts from Poland shall take part and shall make reports during the Conference on palliative care in Kyiv. Also, experts from Poland participated in 3 round tables (in Kyiv and Tcherkassy) with public health officials, doctors
Development and advocacy of implementation of protocols (formulars) of doctoral substances usage while pain therapy	All-Ukrainian Council for patients rights and safety	On November 14, 2007 the project is in the process of realisation
Support of participation of the civil society in Interdisciplinary Task Force on Improvement of Palliative Care Legislation	All-Ukrainian Council for patients rights and safety	On November 14, 2007 the project is in the process of realisation