The Legal Research and Strategy Institute

# Human Rights In Healthcare — 2012

Human rights NGOs report on respect for the right to health in Ukraine

> Kharkiv «Prava ludyny» 2013



General editing A. O. Rokhansky

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"Human Rights in Healthcare — 2012" human rights NGOs annual report provides an analysis of the situation with human rights in healthcare in 2012. The report traditionally includes two parts: "General" and "Special".

The "General" part includes a study of the healthcare system's reform launched by the Government of Ukraine in pilot regions, but affecting Ukraine at the national level. Also the "General" part provides a description of the cases litigated at the European Court of Human Rights in 2012 on defending patients' rights in the frame of the cases vs. Ukraine as well as analysis of the national courts' practices in "medical cases" in 2012.

The "Special" part narrates on the situation with the rights of the people living with HIV, access to opioid substitution programs, and human rights in palliative care. The specific chapters provide information on LGBT rights in healthcare, cases of violations of the right to healthcare at penitentiary settings.

The Report's special chapter on access to healthcare for Roma was expanded; it covers the strategies of the rights-based aid to the community through introduction of Roma health mediators system.

One more important topic of the publication — "Vaccination: the right or the duty?" — has not been formulated by means of legislative documents by healthcare providers and lawyers, although the public discussions have been in progress for a long time already.

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#### FROM EDITORS

uman rights work entails systematization of the civil society organizations' activities, identifying the most frequent cases of human rights abuse as well as efficient strategies to restore the infringed rights. The authors of the "Human Rights in Healthcare — 2012" annual report hope that they have succeeded in reaching the objective for this publication: to study the most significant events that occurred in 2012 in Ukraine from the perspective of respect to human rights in healthcare, including international standards; to provide recommendations, and if these recommendations are implemented, the situation will improve, according to experts' opinion.

Also the authors believe the publication will promote more active discussion on reform of the healthcare system to comply with human rights standards. We have hopes that the success stories on advocating for the vulnerable populations' rights as well as litigation cases will enrich the human rights advocacy tools' inventory of civil society organizations in Ukraine.

Institute for Legal Studies and Strategies NGO expresses its sincere gratitude to the civil society organizations that took part in drafting the report or contributed the information about their efforts to the special chapters:

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Andriy Rokhansky Institute for Legal Studies and Strategies, Head

#### INTRODUCTION

ccording to the State Statistics Service of Ukraine, the natural population loss was observed in 2012: it reduced by 124,996 persons<sup>1</sup>.

Despite the launch of perinatal centers in 2011–2012<sup>2</sup> in Kirovohrad, Donetsk, Kharkiv, Zhytomyr, Dnipropetrovsk, Kyiv, Simpheropil and Poltava, the infant mortality incidence<sup>3</sup> has not reduced, it even shows the trend to grow — 4769 (4704 in 2011).

In 2012 twice as many babies (aged less 1 year old) died of cancer (42 babies in 2012, 26 — in 2011).

Cancer-related mortality rate among adults has also grown — 204 deaths per 100,000 in 2012 (in 2011 — 194.9).

Human immunodeficiency virus-related diseases and the respective mortality rate have remained at the same level — 12.1 deaths per 100,000 (5,042 Ukrainians).

It is a common knowledge that modern healthcare requires significant investments both in R&D and resources in general. The above mentioned random examples of the healthcare system's inefficiency may be addressed only if the funds are allocated at the large scale.

The aggregated State Budget of Ukraine for 2012 includes the health expenditures to the tune of 55.2 billion UAH; it exceeds 2011 fig-

ure by 12.9%. However, taking into account the growth of prices for medicines, medicinal goods and services the residents of Ukraine experienced in 2012, this 12.9% increase of the budget expenditures will not even compensate to keep the health system normally functioning.

The Communications Department at the Ministry of Finance refutes the information on "cutting" the expenditures for healthcare in 2013<sup>4</sup>:

"Speaking about the inadequate funding for the healthcare system expenditures, it is no secret that this problem has not appeared today; it was on the agenda for the previous Cabinets of Ministers as well.

The problems have been stockpiled in the healthcare system during many years. They cannot be resolved overnight, because there is a need in restructuring the whole system of healthcare delivery and search for new sources of funding (not only public funds).

Bearing this in mind, last year a pilot project on the healthcare system reform has been launched in 4 regions within the frame of "Wealthy society, competitive economy, efficient state" program of economic reforms for 2010–2014.

Particularly, the pilot regions will become the model sites to test the new strategies on organizing the work of healthcare facilities and the methods of their funding, to differentiate the healthcare expenditures depending on the types of healthcare. These steps will contribute to bet-

<sup>&</sup>lt;sup>1</sup> http://www.ukrstat.gov.ua

<sup>&</sup>lt;sup>2</sup> New life — new quality of motherhood and childhood" national project.

<sup>&</sup>lt;sup>3</sup> January–November 2012.

<sup>&</sup>lt;sup>4</sup> http://www.minfin.gov.ua/control/uk/publish/article?art\_id=353252&cat\_id=326268

ter quality of healthcare services and expand the opportunities regarding the healthcare affordability and quality.

Testing the healthcare system's reform in pilot regions and replicating this experience in other regions will provide for restructuring and optimizing the network of healthcare facilities. This step, in its turn, will promote the introduction of mandatory medical insurance system and, respectively, raising additional funding for healthcare".

Obviously, the healthcare reform looks brilliant and advanced in theory, on the web sites of the MoH, regional state administrations; but how is it implemented in reality? We have to find out using the evidence provided by the reform witnesses: pensioners, young mothers, doctors,

rural regions' residents, youth and the people with disabilities.

Also human rights NGOs primarily focus on the problems of those groups, which are not in the position to help themselves without external support: mental patients, individuals detained by the police or convicted for criminal offences, people living with HIV, etc.

The right to health constitutes a fundamental inalienable right of an every individual. Realization of the right thereof is an inalienable component of realization of the right to life. The given chapter of the human rights NGOs' report covers the cases of the breach of the right to health by the state of Ukraine and includes recommendations for human rights NGOs to restore the infringed right.

# GENERAL PART

### Chapter 1

## ON HEALTHCARE REFORM IN UKRAINE

«Healthcare's condition is a fasade of the government»<sup>2</sup>

In Donetsk most of the people polled within the survey conducted by Radio Svoboda have never heard about either the healthcare reform or about family doctors<sup>3</sup>

A reader's comment: I do not know about Donetsk, but Donetsk region residents know about the reform very well. For example, one healthcare facility was located in Zhdanovka, a small town 5 km from Yenakiyevo, and everything was more or less all right and customary. Now there are two clinics there: the old one and the new one — Family Medicine Clinic. Now if you want to consult a surgeon, you are to attend a family doctor first. The latter may refer a patient to a surgeon, if there is a need, i. e. to the old clinic. The procedure is applicable to all requests. It is impossible to reach the old clinic without mediation of the "family" one.

A reader's comment: Have most of the people not heard? You'd better ask the healthcare professionals at dentist clinics and their patients. They are being "improved and stabilized" for a year already.

Most of the facilities were reformed to such an extent that they were expelled from their premises, which had been traditionally located in city downtowns. We managed to stand our ground in Donetsk, although the city council tried to pressure the dentist clinic with the support of Security Service of Ukraine (a search, etc.). Their real target was to take over the premises near "Donetsk City". The dentists were supposed to be relocated to Putilovka over there — to the half-ruined building.

Here the reader means the oldest dentist clinic in Donetsk; it has been operating in the city for more than half a century. 27 years ago it was the first in the region to switch to self-sustainability operational mode, preserving its municipal ownership status. The doctors managed to survive during the hardest times of the first years of "independence". Currently it provides treatment for 40,000 patients. Patients include many pensioners and the disabled individuals are provided with discounts and benefits.<sup>4</sup>

# The location on the map: the district where the healthcare reform proved to be unsuccessful is called Konstantynivsky<sup>5</sup>

Residents of some villages in Konstantinovsky district of Donetsk region insist on reviewing the novelties in the healthcare system. According to

<sup>&</sup>lt;sup>1</sup> The chapter has been drafted by Andriy Rokhansky, Maryna Hovorukhina, Mykhaylo Tarakhkalo.

 $<sup>^{\</sup>rm 2}$  Mykola Dzhyha, Vinnytsya Regional State Administration, Head.

<sup>&</sup>lt;sup>3</sup> http://www.radiosvoboda.org/media/video/24705136. htmlNo.relatedInfoContainer

<sup>&</sup>lt;sup>4</sup> http://pauluskp.livejournal.com/196852.html

<sup>&</sup>lt;sup>5</sup> According to the publication "062 Donetsk". http://062. ua/news/v-donecke/kto-vedet-statistiku-smertnosti-lyudi-umi-rayut-iz-za-novoy-medicinskoy-pomoshchi

them, the closure of the 24h in-patient hospital at former Yekaterinovka District Hospital (it was transformed into an out-patient facility) resulted in the fact that the village residents were bereft of the right to timely healthcare.

«What do these officials think about? They should come here and look: how was it possible to destroy the hospital that had worked since 50ies of the last century. And it was fully renovated last year", — one of Yekaterinovka old residents says.

#### Yekaterinovka residents

«Do you care to know many folks died within the last 6 months just in our village? One woman died: her blood pressure was unstable and sugar level in blood was high. Earlier there was an opportunity to be admitted to a hospital and have a course of injections administered. And now what? There are no relatives. Who will bring her to Konstantinovka? The city facilities do not admit rural residents to their single inpatient hospital. That's how she died after her next health crisis".

"A fellow, aged around 45, came — he was severely beaten. Where could he have been hospitalized? He just left and died on his way home", — reports another villager.

The community members are also indignant that the healthcare reform is the reason that there is no healthcare staff to treat children from rural areas. 10 *ambulatoriyas* (an out-patient small healthcare facility) and 23 FAPs (feldshersko-akushersky punkt — an even smaller facility where services are provided by a medical attendant) organized within the frame of Konstantinovka primary healthcare center (network) has only one pediatrician in staff who treats children, being located in the district center.

Nothing to do, healthcare professionals state, it is not possible to get funding for more than one salary of a children doctor (Konstantinovka district's population is 22,000).

## (3)

#### Decay of the pediatric care

Volyn oblast is not included into the list of the regions where "healthcare experiment" is piloted. However, Fedir Koshel, Lutsk City Council Healthcare Department Chief, states that healthcare reform has been launched a couple of years ago in Lutsk. The problems in the oblast are familiar: Lutsk mothers do not want their children being examined by a family "doctor" who have been re-trained and got an additional qualification after graduating from 6-month course. The statistical data is the confirming evidence: primary healthcare center operating at the 1st Lutsk City Polyclinic provides services for 50,759 adults and only 342 children.

Reform — in its direct sense — requires significant financial investments. First of all, the funds are needed to purchase up-to-date medical equipment. But if physicians continue to work using current equipment, why launch this reform?<sup>6</sup>

"Why break if it works now?" — a physician with 20 year work record says — "They want all of us to turn into family doctors. This is nonsense. One must be trained within 8-10 years, not six months, to become a family doctor. Organisms of an adult and a child are somewhat different; so well the methods of treatment are. The difference is even bigger for an infant aged under 12 months. I am afraid these reforms will destroy pediatric service and that's all. Family medicine will start to work when our medical universities will supply respective professionals. And one should not forget about diagnostic equipment our polyclinics have now and the access to it. One should purchase the equipment first and train professionals; change of the by-laws and signs on hospitals is the next step".

<sup>&</sup>lt;sup>6</sup> http://vidomosti-ua.com/news/48748

## 4

#### "Fine for failure to appear"

As "Segodnya" newspaper reports<sup>7</sup>, announcements declaring about the need to register at polyclinics "in compliance with the Law of Ukraine "On the procedure of healthcare system's reform implementation" appeared almost on signboards of every house. Doctors, just like competing politicians during the pre-election campaign, call the residents to subscribe to their facilities. They promise to provide sick leaves without any examination and consult patients even in the night. The reason is quite clear for the doctors' conduct: every single patient means additional funding.

The announcements arouse surprise with communities' members; some suppose that those who will fail to register shall pay a fine. "I called the polyclinic. Was told it was mandatory. And one will be fined if one fails to appear", — reported a woman from Kyiv living in Ernsta Street.

Physicians state they are not ready so far to carry put the functions imposed on them within the frame of the pilot project on healthcare system's reform<sup>8</sup>

MoH officials agree that "family medicine in Kyiv is far from ideal as of now", but they note that "the newly-created family medicine centers' activities have stabilized: the conditions for general practitioners' work have been created, some pieces of equipment have been purchased".

However, family doctors themselves do not share this optimism.

"Inappropriate condition of equipment and other material assets and lack of preparedness of doctors to implement the functions they are imposed with discredits the very idea. Patients have to attend family doctors, but family doctors are not ready yet to perform their functions", — **Ruslan Dobrovolsky**, family doctor, says.

In particular, currently clinics and family medicine out-patient facilities have to be open for patients of different age groups in compliance with the old system.

"It's great our doctor is a former pediatrician, we are lucky, she knows how to treat a child. But I am angered with the situation when children and adults have to wait for a consultation sitting in the same location; so children have contact with sick adults. It is the reason why I choose not to attend the facility, I report to them over the phone, so that they will have something to fill in the medical records", — Alina, a mother of a young child, says, who have to entrust her baby's health to a family doctor.

## 5

#### One more failed attempt to introduce medical insurance system since January 1, 2013

The healthcare reform's goal includes a statement that re-structuring and optimization of the network of healthcare facilities, stratification of healthcare into several tiers and other activities are implemented in pursuance of a further opportunity to introduce general mandatory medical insurance system. The system is expected to crucially improve the financial "climate" in healthcare.

On August 13, 2012 one more draft Law "On general state mandatory medical insurance" was submitted to the Parliament of Ukraine with the obvious purpose to further equip the health-care reform with respective policies and laws.

The key idea of the draft law was to introduce a general state social medical insurance since January 1, 2013. It was supposed to include three tiers. According to the draft law, these three tiers meant the following:

 The first tier — solidary system of general mandatory medical insurance based on solidarity and subsidies; insurance payments were supposed to be paid by the Medical Insurance Fund;

<sup>&</sup>lt;sup>7</sup> http://news.liga.net/ua/news/capital/728583-u\_stolits\_budut\_prokhoditi\_vibori\_l\_kar\_v.htmNo.

<sup>&</sup>lt;sup>8</sup> http://www.radiosvoboda.org/content/article/24705089. html

- The second tier savings-based general mandatory medical insurance system based on the principle of savings done by the insured individuals to the Savings Insurance Fund;
- The third tier private medical insurance system based on the principle of voluntary involvement of citizens.

The first and the second tiers of the medical insurance system constitute the general mandatory medical insurance system. The second and the third tiers constitute the savings-based medical insurance system.

The draft law included the provisions ensuring an opportunity for citizens of Ukraine to participate and get insurance payments at different tiers of medical insurance system. The draft law also included the details on principles, foundations and mechanisms of the general mandatory medical insurance system's functioning. It described its subject-matter, subjects, their rights and duties, the groups of individuals who are legally bound to participate in the general mandatory medical insurance system, the mechanism of calculating and payment of insurance premiums.

It was planned that the mandatory medical insurance system must be regulated by the following types of contractual documents:

- medical insurance policy document signed by the Medical Insurance Fund and/or Savings Insurance Fund and insurers in favor of the insured person;
- the agreement to be signed by the Medical Insurance Fund and/or Savings Insurance Fund and a healthcare provider; the agreement is supposed to include the list of healthcare services, their cost, amounts, methods and timeframes for treatment, prevention efforts, and responsibility;
- the agreement on cooperation to be signed by various healthcare providers; it is supposed to include the list of healthcare services provided by involvement of specialized doctors or re-

ferrals of a patient to consult practitioners and get services at other facilities.

But one should note that, according to the Chief Expert Department at the Parliament, the suggested amendments to the draft Law, including those on canceling the Laws of Ukraine "On mandatory state social insurance related to the temporary loss of ability to work and the costs related to births and funeral" and the Law of Ukraine "On mandatory state social insurance related to accidents while discharging duties and occupation-related diseases causing the loss of ability to work" and others will result in destruction of the whole current system of the mandatory state social insurance<sup>9</sup>, this system established by the Legislative Fundamentals of Ukraine on mandatory state social insurance and the key laws in the sphere of social insurance.

In general, the analysis of the draft law shows that it will not ensure achievement of the goals and objectives declared in its Explanatory Note; its implementation will not promote successful resolution of the key problems of Ukrainian healthcare system's functioning and development; these problems related to ensuring the constitutional rights of citizens of Ukraine to free healthcare and creating "conditions to provide efficient and affordable (for all citizens) healthcare services" (Article 49 of the Constitution of Ukraine).

# 6 Dnipropetrovsk: pediatric care is totally destroyed as an aftermath of the health-care reform

As Tatyana Okhotnik, mother of two children of pre-school age and an activist, reported to "Dnepropetrovsk. Kommentarii" publication, "in spring mothers experienced the problem at polyclinics: when they came there, they had no idea where to find doctors. For example, [the

<sup>&</sup>lt;sup>9</sup> The conclusion made by Chief Science and Expert Department of 09/26/2012, http://w1.c1.rada.gov.ua/pls/zweb2/web-proc4\_1?pf3511=44150

<sup>&</sup>lt;sup>10</sup> http://dnepr.comments.ua/news/2012/06/01/112313.html

clinic] at Vorontsova street had its three consulting pediatric rooms re-located to the polyclinic for adult population, to the building, which was inappropriate for its purposes".

"Polyclinic for children located on Yubileyny was closed: its premises were passed to the notary's office; the clinic was partially closed in Novomoskovsk. In fact, all pediatric polyclinics ceased to exist",- Tatyana summarizes the information on "excesses" of the healthcare reform the parents shared at city web fora.

The key problems included the fact that all categories of people: adults, children, pregnant women, the sick and those who are healthy have to wait for their turn in a queue to a doctor and doing their medical tests at these newly established out-patient facilities. The second problem is that there is a very small number of family doctors with adequate qualification. To cap it all, the polyclinics built in Soviet era are not fit to accommodate the division of patients' flows.

According to activists of "For our children", the independent parents' movement, who gathered together through the use of Internet, the authorities undertook the reforms in an unprepared fashion. The pediatric consulting room is often located near a psychotherapist's; [the clinic] ay Sofya Kovalevskaya street has it located near the room where a skin diseases and STI doctor treats patients. [the facility] in Novomoskovsk placed testing laboratory near the X-ray test room. The mothers in Novomoskovsk often witnessed how prison inmates were brought for medical examinations whereas the services delivery for the regular patients was in progress. One more example for Novomoskovsk: a mother came to the out-patient facility where she was registered in accordance with her residence with a referral to do a cardiogram test for her child. But she was denied to get the service with a reason provided by the "adult" doctors that they did not know how to interpret a "pediatric" cardiogram.

Thus, the transformations are undertaken rapidly; no preliminary training for the doctors, preparing the rooms, educating activities for patients are done.

E. g. the polyclinic for children located in Pobeda neighborhood, Kosmicheskaya Street, provided services for 15–20,000 children. Within one week, in compliance with the decision taken by the regional healthcare department, this polyclinic was re-structured. 6 pediatricians were transferred to [the clinic] at Heroyev 22: three out-patient facilities are established there.

"The final outcome is: huge queues to the clinic reception desk, patients fight to get respective permits to visit a doctor; one has to wait for two hours to get one's blood tested. If a mother with a child wishes to consult an otolaryngologist, she has to attend a clinic at Heroyev Street, wait in a queue to visit a pediatrician first there, get a respective referral, go to Kosmicheskaya Street, get a permit to see a doctor and, finally, to get services. If one wishes to get one's blood tested, one has to visit the facility at Fuchik Street, previously attending the clinic at 22 Heroyev Street. Earlier all services were available in one building: doctors of all specializations, out-patient facilities, massage, remedial gymnastics" — the parents complain.

The parents are outraged with the methods of the reform: "On the one hand, a new perinatal facility has been unveiled; hundreds of thousands hryvnas may be spent there to save one child; on the other hand, the pediatric care is being destroyed. There is no logic in it. Within one week they broke the system that had been developed for dozens of years".

Iryna Derevyanko, an activist, made a statement: "What is the sense to open a perinatal facility, to bear children, to save children, if they are afterwards serviced at an out-patient facility, expose them to the risk to contract all adult diseases?" Many mothers complain that some children are diagnosed with bronchitis; however, after dressing and undressing the child, move or transfer to the other building, standing in a queue to get medical examinations done — the child is often diagnosed with pneumonia by the specialized doctor.

Tatyana Okhotnik added that "we were fighting for two months to return Tuesday as a tradi-

tional healthy child day. Earlier no adult patients had been allowed to enter the clinic on that day. Now it is impossible: general practitioners provide services for patients every day. Most of these patients are sick adults".

Parents agree that healthcare reform is necessary. However, transformations should be undertaken in compliance with the needs in a specific city, district, or a neighborhood. According to their opinion, the massively populated areas in cities should preserve their pediatric clinics. The healthcare services provided at smaller out-patient facilities should be applied in distant locations.

## 7

## 12 healthcare facilities will be closed down in Dnipropetrovsk region at the same time<sup>11</sup>

The decision on closure was adopted by Dnipropetrovsk Oblast Council at its session on December 21, 2012. Neither the outraged patients rallying near the council's house nor warnings expressed by the opposition in the session's room had any effect over the pro-government's majority voting. The authorities assure that innovations are necessary to dispose of the public funds more effectively; that some healthcare facilities will be restructured by uniting them with the other ones within the same professional scope; that healthcare professionals will retain their jobs. In the meanwhile, the opponents of the decision state: neither this decision nor the whole healthcare reform in the oblast was discussed by the public.

It is unacceptable to adopt such decisions without public hearings and public discussion. There are hospitals that are merged: but they are located on the opposite banks of the Dnipro river and there is bridge between them. Hospital No. 7 is merged with ambulance hospital. Who suggested such an absurd? Where is the logic? I am aware that it is some internal strife and destruction. But how can they exterminate our doctors like this?

<sup>11</sup> Liberty Radio. http://www.radiosvoboda.org/content/article/24805620.html

Our medical experiment was made a laughing stock for the whole country; but people are crying, because children die, the elderly die", — opines **Viktoriya Shylova, council member.** 

«I ask: don't touch Dnipropetrovsk clinics. One more moment: the healthcare facilities' supervisory boards are not aware of their reorganization yet. Why do we push our local government like this?» — Kateryna Vidyakina, the council member adds.

In the morning on December 21, 2012 around two dozens of patients of City Hospital No. 7 gathered near the building of Dnipropetrovsk Oblast Council; it was 15 degrees below zero Celsius. The people came spontaneously, they had no broadsheets or prepared demands. But they found out that it is forbidden to rally on the square near city Christmas tree; the police set the cordons and demanded that the protesters would leave the place.

Heorhiy, the patient who has been visiting Hospital No. 7 for many years, is angered: the facility had a good cardiology department. According to him, he will have nowhere to go to have his heart problems attended. "It is not like when you've got pain in your belly: take a pill and you are OK. This is heart. It stops — and you're done" — noted the man being interviewed by Radio Liberty.

# 8 The authorities do not care for the voice by civil society, independent trade unions and local government council members<sup>12</sup>

Viktoriya Shylova, Dnipropetrovsk oblast council member, calls the healthcare reform "a plague". As Ms. Shylova notes, 95% of the oblast residents are totally against the reform in the current format: it has not brought the healthcare closer to people, but just the opposite, "it moved it away from people to the closest healthcare facility by 80–100 km". This has not been noticed only by local officials.

<sup>&</sup>lt;sup>12</sup> "Healthcare reform: is it a new improvement or a ticket to the Kingdom come?" http://life.pravda.com.ua/health/2012/05/3/101606/

Serhiy Shubnikov, the head of the "Mir" city NGO, uniting the workers who got disabled while discharging their work duties and the family members of the workers perished at their working places, provides his comment regarding the situation: "Within 15 years standards of healthcare are regularly being changed. Earlier I had been entitled for a month of in-patient treatment, then this term was more and more reduced. Now if a patient does not recover within 7 days, a professional qualification of a doctor is put under doubt. But there are situations when patients are not able to recover within such a short term, e. g. when a patient after a heart attack is admitted to a hospital".

"Mir" civil society organization promoted founding of an initiative group "Against health-care reform" in Dnipropetrovsk region. Currently its activists undertake energetic efforts to inform the authorities that the healthcare reform should be stopped. The dialogue with the authorities switched to the traditional regime: correspondence with no hope for changes. Having abandoned their hopes, the people made up their minds to hold a peaceful assembly to initiate a local referendum.

However, after the notice on holding a rally on April 27 in Dnipropetrovsk was filed, Serhiy Shubnikov received a call from the Administrative Court. He was told that Dnipropetrovsk City Council filed a complaint and the court ruled out to ban the peaceful action.

"Pursuant to Article of the Constitution of Ukraine, human health is the highest value of the state. The Constitution also guarantees freedom of expression. Where does this ban push us towards to?" — Shubnikov asks.

Before holding the peaceful assembly in Dnipropetrovsk representatives of the Free Trade Union of Medical Workers of Ukraine (FTUMUU), "Against Healthcare Reform" initiative group and "Mir" NGO came to Kyiv to tell about their problems. They state that they had to resort to this effort because they had no chance to inform about the situation at the regional level. "All communication channels in Dnipropetrovsk region are blocked. We are not allowed to come to any local TV channel, therefore we hold a press conference here in Kyiv, so that our voices are heard..." — Viktoriya Shylova says.

"This healthcare reform model is designed for officials, not for people" — Serhiy Shubnikov argues.

Nobody argues against the need to reform the current healthcare system, but few expected such outcomes.

In some situations it's getting pretty absurd. As Viktoriya Shylova reports, the funds allocated for 6 months for healthcare are all spent to purchase a CT scanner for 8 million hryvnas. It is not used within 6 months until the moment the respective software is purchased (at nearly the same price). The CT scanner's own maintenance costs 5 million hryvnas per year. The local hospital budget does not include this money, obviously. Therefore, the "price" is set for patients who are to "donate" from 380 to 1500 hryvnas.

The pilot oblast is against such an experiment being conducted using human beings as experimental guinea pigs. So, the guests from Dnipropetrovsk ask: does it make sense to scale up the healthcare reform?

## 9

## "The ambulance won't come to your place anymore"

Soon the emergency healthcare centers will be founded in Ukraine: they will comprise the emergency care departments and the single dispatcher service with GPS navigation system. However, the doctors themselves have some grounds to state that this reform will be disfigured.

Maksym Ionov, the doctor at Kyiv City emergency healthcare station, the Chair of the Free Trade Union of Emergency Healthcare Workers, reports<sup>13</sup>:

<sup>&</sup>lt;sup>13</sup> Pain: more details on the problems with emergency care on "Maidan" http://maidanua.org/2013/01/likar-maksym-ionov-shvydka-do-vas-bilshe-ne-pryjide/

In summer 2012 the Parliament of Ukraine hurriedly adopted an absolutely "raw" and unprepared bill: the Law of Ukraine "On Emergency Healthcare". It came into force since January 1, 2013. That means that the Ministry of Healthcare of Ukraine currently is entitled to adopt orders and policies at their own discretion, having no regard to the examination procedures by experts and lawyers from other government bodies.

More than that, on November 21, 2012 the Cabinet of Ministers of Ukraine adopted the decrees clearly outlining the standards for "Emergency Healthcare" (the new title in Ukrainian — "Ekstrenna Medychna Dopomoha" shall be used in compliance with the Law since January 1, 2013). The standards include: the time for an ambulance to arrive since the moment of a call is clearly specified (10 minutes in an urban area, 20 minutes in a rural area); the calls are classified into "emergency" and "non-emergency"; the stations for temporary stay of the ambulance teams have been introduced. These interventions were supposed to result in creation of the Centers of Emergency Healthcare and Medicine of Disasters with emergency healthcare departments and the single dispatcher service with GPS navigation plus stations for temporary stay of emergency care teams.

What is going on in reality?

Maksym lonov: The quality of healthcare or rapid arrival. One will have to forget about the quality of healthcare in future, and I will explain why. Currently the officials prioritize the time spent to arrive and further emergency admission to a hospital plus total austerity measures in everything. The next obvious step in development of the priorities will be a criterion: "managed to bring a patient to hospital/failed to do so". One step more in this direction and one will have to forget about the quality of healthcare delivery.

Because there will be the single indicator against which the quality of service will be assessed — "managed to bring — failed to do so", and nobody will care about the quality of care to be provided. And who will provide quality healthcare? A paramedic?

Since January 1, 2013 just a medical attendant is authorized to visit a patient after a call is received. In a couple of years, it will be a paramedic. Having no medicines, no equipment, no assistants (or just with a driver), the worst thing is that they will lack even medical experience. Me as a doctor am able to differentiate between hospitalization of a patient with an acute coronary syndrome (cardiac infarction) with intensive therapy applied, when a patient is treated with a defibrillator (qualification of a medical attendant is enough) or urgent care with thrombolysis at pre-admission stage as our cardio resuscitation teams do.

There is big question: why setting a standard of 10 minutes for the emergency healthcare team to arrive, nobody raises an issues of terrible conditions of roads, worn-out medical cars, traffic jams, aggressive attitude of other drivers, totally unreadable plates with numbers on the buildings and street names or lack of these plates whatsoever, the conditions to enter into yards of blocks of houses or hospitals? And this list may be continued.

GPS navigators. Many healthcare professionals and the public were excited with perspective of using GPS-navigation. The healthcare professionals were much relieved that it would be easier and faster to find the address. But it was not so. GPS-navigators were installed not simply for the address search but to ensure control and monitoring over the ambulance team, so that the dispatcher could track at his screen where each team was and what it was doing. In fact, this information was always known. The teams still had to be very inventive using these maps while having the problems to identify the best route to the necessary location. But the total control over the use of fuel strengthened, and the healthcare facility administrators do not care for the traffic jams, because they are not marked on the map.

## Extra temporary stations for emergency care teams.

The experiment on piloting this model appeared to be totally unprepared and unorga-

nized. Formally 30 such stations were installed, but in reality the emergency care teams were sent to stay on the alert near clinics or other healthcare facilities. In some cases they had to stay right on the street, without any opportunity to attend their needs (have meals, hygiene procedures, etc). These factors led to pronounced protests and objections both by the public and healthcare providers who had to work under terrible conditions.

Qualified staff. Within the recent ten years the lack of professional staff is one of the key problems for the emergency healthcare service. The causes are simple: labor conditions deteriorate; salaries are beggars-like; young professionals are not offered with any incentives; experienced doctors and medical attendants leave for calmer and better paid positions in private healthcare.

Maksym lonov: The healthcare system reform is in full swing here. According to officials, the reform means better use of healthcare facilities; in simple words and in reality that means their closure, sale or total extermination. The same may be applied to emergency healthcare system. The officials got to "re-structure" it, but they did not invest a single cent. In consequence, that means that the old structures will be destroyed, but they will not install new ones. It is impossible to build a house without money, without buying any construction staff. But our Ministry of Healthcare officials believe that it is.



#### "Reformed" pediatric service in Vinnytsya

Olha, a Vinnytsya resident, reports: "It is about healthcare reform. My son is 10 years old. We have been attending a pediatric polyclinic for 10 years as well, we do it frequently. But we've never witnessed the things we saw. We came to consult an ophthalmologist. There were crowds of people near his room, so we got to come back home. I made up my mind that we would come early in the morning the next day. The doctor's office hours are twice per week at 9:00–15:00! Until the

reform it was possible to visit the doctor every day! When we came at 9:00 before the consulting hours started, there were a lot of people there; we even had the impression that nobody had left since the previous day... There were 30 people so, I cannot be sure. And I supposed we would be one of the first ones! We found out who was the last in the line and started to wait. We consulted the doctor after 3 pm. So we were waiting in the line for six hours! Six! Everybody got tired of waiting. We have never experienced a thing like this within the previous 10 years. Yeah, we had been waiting in lines. Sometimes 30 minutes, sometimes, one hour. But not six hours, it is a full working day almost! Terrible! The doctor was tired, I understand her mood. No lunch break or other breaks. Everybody is guite nervous, Children are hungry. Who could have guessed it would take for so long?"14



# The rural community members ask the President to exclude their village from the healthcare reform piloting

Voronovytsya residents — a village in Vinnytsua district, 20 km distance from Vinnytsya, gathered at the community general meeting. They adopted a resolution and sent an address to the regional state administration and the President of Ukraine with a request to exclude their village from the healthcare system reform pilot. This action was undertaken in response to the intent of the authorities to close the large district hospital: it had provided services for 20,000 residents from Voronovytsya and neighboring villages<sup>15</sup>.

"Now they call it "optimization", — Viktor Stetsky, the head of Voronovytsya village council reports, — "although in fact this is a closure. They gradually reduce the number of employees as well as number of beds. It has been reduced

<sup>&</sup>lt;sup>14</sup> http://zotov-news.blogspot.com/2012/08/blog-post\_27.ht ml?showComment=1348840302830No. c2413223154375357146

<sup>&</sup>lt;sup>15</sup> http://amm.net.ua/pid-vazhkim-chobotom-medichnoyireformi.html

from 80 to 50 already. And what do beds mean? It is the reduction for healthcare professionals and the budget funding. In the result many patients don't have access to proper healthcare services. Official number of the patients (neighboring villages included) provided with services at our hospital is 14,000, the unofficial estimate is 20,000. Many Tyvriv district residents cannot reach their district hospital — there is no transport communication — therefore, they come to us. We do not deny them in services. All the more so, historically the hospital was constructed by common efforts of neighboring collective farms. But here we have a problem with ambulance cars. Tell me, who must come to a patient who is not registered with our hospital? One more thing... now we have family doctors. Let's imagine: a patient calls a doctor to attend him/her at home. But how can a doctor come to the neighboring villages? The emergency healthcare service is a service independent from them. More than that, they want the emergency healthcare service to be transferred to the medicine of disasters. But I don't perceive any logic — there have been no disasters here for ages".

## **(12)**

#### **Healthcare Reform Interim results in 2012**

- 1. The Pilot Healthcare reform system' legal framework was not harmonized with the Constitution of Ukraine, Budget Code of Ukraine, Administrative Code of Ukraine, Civil Code of Ukraine, The Code of the laws of Ukraine on labor, the Law of Ukraine "On Remuneration of Labor" 16.
- 2. The processes of unconstitutional reduction of the healthcare facilities' network and installing fees for healthcare services persisted.
- 3. The Law of Ukraine "On Emergency Healthcare" does not take into account the specific features of the emergency healthcare delivery. The infrastructure of administrative and territo-

rial units is not considered, including road conditions and the public transportation system.

- 4. The primary care units in pilot regions, especially those outside regional center in rural regions, are located, giving no consideration about their accessibility for patients, including the elderly and those with limited capacity to move.
- 5. As of late 2012 the Primary Care Centers in pilot regions are not staffed with healthcare professionals with adequate qualifications; they also do not feature the equipment for diagnostics and treatment of the most frequent diseases, injuries, poisonings, pathological, physiological (pregnancy) conditions.
- 6. The reform's lack of transparency. On October 24, 2012 the Cabinet of Ministers adopted the Decree No. 1113 "On adoption of the Procedure of setting up hospital districts in Vinnytsya, Dnipropetrovsk, Donetsk regions and in the city of Kyiv". Article 12 of the Procedure on holding consultations with the public on public policy development and realization issues (adopted by the Decree of the Cabinet of Ministers of Ukraine No. 996 of 10/03/2012) determines that a draft of the Decree of the CMU shall be mandatorily subjected to public discussion. Item 8 of the Explanatory Note to the above mentioned Draft of the Decree of the CMU includes a statement on posting it on the MoH web site for discussion. But this document has never been posted at the MoH web site<sup>17</sup>.
  - Negative consequences of the healthcare reform's implementation continue
  - The healthcare practitioners specialists in specific diseases — are lost, because they work in different areas.
  - The pediatric service is in the process of collapse.
  - The public associates the healthcare reform with worse quality of healthcare, especially for vulnerable populations.

<sup>&</sup>lt;sup>16</sup> More details in "Human Rights in Healthcare — 2011» http://library.khpg.org/index.php?id=1340911384

<sup>&</sup>lt;sup>17</sup> http://medreformadn.blogspot.com/2012/11/blog-post\_ 21 .htmlNo. more

## **(13)**

#### Recommendations

- 1. To bring the provisions of the Law of Ukraine No. 3612 of 07/07/2011 "On the procedure of implementing the healthcare system reform in Vinnytsya, Dniprpetrovsk, Donetsk regions and in the city of Kyiv" as well as the Law of Ukraine No. 3611 of 07/07/2011 "On introducing amendments to the Fundamentals of the Laws of Ukraine on healthcare" in compliance with the Constitution of Ukraine, Budget Code of Ukraine, Administrative Code of Ukraine, Civil Code of Ukraine, The Code of the laws of Ukraine on labor, the Law of Ukraine "On Remuneration of Labor" 18.
- 2. To impose a ban on cutting the network of healthcare facilities and introduction of paid services in compliance with the valid Constitution of Ukraine.
- 3. To strengthen the supervision of the law enforcement bodies, prosecutor's office over the processes of "re-organization" of healthcare facilities and respect to the valid laws in the area of administrative and labor law.
- 4. To strengthen civil society's monitoring over the implementation of the healthcare system reform.
- 5. To enhance the transparency of decision-making on all issues of healthcare reform's

- implementation, including public discussion of the policies, which require use of the transparency tool.
- 6. To disseminate the information about the events and stages of the healthcare reform implementation in advance: before the actual administrative steps are undertaken.
- 7. To develop Primary Medical Care Centers through staffing them with specially trained professionals with respective qualification and taking into account the international experience (up to 10 years of work record).
- 8. To introduce amendments into Article 49 of the Constitution of Ukraine on canceling the provisions about free of charge character of all healthcare services, to guarantee a list of specific free healthcare services (minimum basic level guaranteed by the state).
- 9. Upon introduction of the amendments into Article 49 of the Constitution of Ukraine to specify the sources of funding for healthcare system: state national budget and the mandatory health insurance fund.
- 10. To recommend the Ombudsman of Ukraine to institute a personal supervision over the process of the healthcare system's reform implementation with the purpose to prevent the breach of the inalienable human rights to life and health.

<sup>&</sup>lt;sup>18</sup> "Human Rights in Healthcare — 2011" http://library.khpg.org/index.php?id=1340911384

## Chapter 2

#### LITIGATING TO PROTECT THE RIGHT TO HEALTH IN COURTS.

1 The European Court of Human Rights practices on defending the rights of patients in the cases vs. Ukraine in 2012<sup>1</sup>

Having studied the European Court of Human Rights' practices in 2012<sup>2</sup> and during previous years an inference may be drawn that patients' rights may be protected by referring to the breach of Article 8 of the Convention if the process and outcomes of non-delivery and/or insufficient delivery of medical care were not those that could be considered an act of torture and/or inhuman or degrading treatment. In cases when the consequences of non-delivery or insufficient delivery of medical care are more substantial, one should make a reference to the breach of Article 3 of the Convention and request the Court to deem the tort to be an act of torture and/or degrading treatment or to Article 2 — if the offence resulted in the death of an individual.

The key moment is that the European Court of Human Rights (hereinafter — the Court) did not rule out in 2012 regarding the cases vs. Ukraine on abuse of patients' rights pursuant to Articles 2, 3, 8, 14 of the Convention. The underlying reasons may include: lack of violations of patients' rights committed by the authorities (which does not look to be true) or insufficient competence of claimants from Ukraine, whose claims are recognized ineligible; or they do not file these claims whatsoever.

<sup>1</sup> The Chapter has been drafted by Nataliya Okhotnikova.

Having studied the Court's practices in 2012 one should note that the share of the cases related to protection of patients' rights is very insignificant. In our opinion, this phenomenon may be attributed to several **aspects:** 

- 1. The text of the European Convention does not include a specific article defining the right of an individual to health care.
- 2. The undefined position of the Court how to categorize the types of breaches of patients' rights either referring to Article 2 (the right to life), Article 3 (Prohibition of torture), Article 8 (the right to respect private and family life), Article 14 (prohibition of discrimination).

During the previous years the Court interpreted similar cases of breaches of patients' rights differently, taking into account the consequences caused by the malpractice of a physician or his/her inactivity. If these acts resulted in the death of patient, the Court might rule out that Article 2 of the Convention was breached; if a patient's sufferings were quite severe — it was Article 8; if medical malpractice or non-delivery of care by healthcare providers were related to discrimination of certain individuals on the ground of sex, age, race — Article 14 of the Convention.

3. Complexity and confusing character of these cases as well as the unwillingness of the Court to analyze objectively the deeds committed by doctors and make judgments on them. However, the Court is ready to resolve the issue on availability of thorough investigation (within the frame of criminal proceedings) of

<sup>&</sup>lt;sup>2</sup> See also http://hr-lawyers.org

the damage inflicted to a patient's health by doctor's malpractice or lack of action in a specific country.

However, while studying the judgments against Ukraine ruled out by the Court in 2012, one may perceive certain trends.

Thus, in *Todorov vs Ukraine case (application No. 16717/05, judgment of 01/12/2012)* the Court paid attention to the fact the Ukrainian authorities consistently fail to respect the rights of the patients at penitentiary settings.

Prior to his arrest, the applicant had been diagnosed as suffering from immature cataracts in both eyes and neurodermatitis. Upon his arrival, the applicant was examined by the SIZO medical staff and placed under dispensary supervision for immature aggravated cataracts in both eyes, diffused eczema, and chronic gastritis. During his stay at SIZO the health condition of an applicant deteriorated. The applicant needed an urgent eye surgery to prevent complete loss of eyesight. The applicant also suffered for a set of skin diseases, which complicated the surgery. The Court noted that although the applicant refused the eye surgery, his refusal was allegedly associated with the advice by a healthcare professional who had noted that his skin diseases should be treated first, because the success of the eye surgery depended on it. According to the Court, this refusal was ungrounded. Further on the Court stated that the national bodies recognized the impossibility to provide the applicant with necessary healthcare in SIZO conditions and filed two motions on releasing the applicant from custody. However, both motions were declined by the national courts. In the result the appropriate health care was not provided to the applicant timely. The Court concluded that the national authorities had not undertaken all necessary measures to prevent the loss of an eyesight of the applicant. On 9 September 2005 the applicant was assigned the first (most advanced) category of invalidity on account of complete loss of eyesight. In fact, it was the guilt of government agencies that failed to provide necessary healthcare to the person in need.

The similar breach of a patient's rights that led to severe consequences is observed in "Kaverzin vs. Ukraine" case (application No. 23893/03, judgment of 05/15/2012). According to the applicant, his disability was the consequence of the failure to provide him with respective and, in particular, timely treatment. According to him, his eye injury was not properly diagnosed in January 2001 that resulted in failure to provide him with adequate treatment. The applicant stated that as soon as healthcare professionals identified his injury, he would have been brought to a hospital and examined by a doctor with special knowledge on this group of diseases. The Court attached a particular importance to the fact that the eye injury was not considered by authorities within six months since it had been detected in January 2001. The government did not provide any explanations for the delay in providing the applicant with proper medical treatment. The Court ruled out in its judicial disposition that Article 3 of the Convention was breached by failure to provide an adequate medical care to the applicant to treat his eye injury from January to September 2001.

Unfortunately, in 2012 the Court did not consider purely medical cases against Ukraine. However, the Court's judicial position from the perspective of the Convention's provisions may be illustrated by G. B. and R. B. v. The republic of Moldova case (application No. 6761/09, judgment of 12/18/2012).

The applicants were born in 1968 and 1966 respectively and reside in Ştefan Vodă. They are husband and wife. On 4 May 2000 the first applicant was giving birth to a child. The head of the obstetrics and gynaecology department of the Ştefan-Vodă regional hospital, Mr. B., performed a Caesarean section on her. During the procedure he removed her ovaries and Fallopian tubes, without obtaining her permission. As a result of the operation, the first applicant, who was thirty-two at the time, suffered an early menopause.

Since 2001 the first applicant has been having medical treatment designed to counteract the effects of the early menopause, including

hormone replacement therapy. According to her doctors, she has to continue such treatment until she is between fifty-two and fifty-five years old, after which further treatment will be required.

According to a neurology report dated 5 November 2001, the first applicant was suffering from astheno-depressive syndrome and osteoporosis. On 18 February 2002 the doctors found that the first applicant experienced hot flushes, neurosis and frequent heart palpitations. On 8 May 2002 she was diagnosed with asthenic neurosis. According to the results of an examination carried out by a medical panel on 18 March 2003, the removal of the first applicant's ovaries and Fallopian tubes had been unnecessary and the surgery had resulted in her being sterilised.

On 26 July 2006 a psychiatrist and a psychologist established that the first applicant was suffering from long-term psychological problems and that she continued to show signs of post-traumatic stress disorder.

On 15 March 2005 the Căuşeni District Court convicted B. of medical negligence which had caused severe damage to the health and bodily integrity of the victim. He was sentenced to six months' imprisonment, suspended for one year. The court referred to medical reports and found, inter alia, that B. had failed to inform the applicants of the sterilisation until ten days after the event. The first applicant's ovaries could have been preserved, but B. had failed to do so.

On 11 May 2005 the Bender Court of Appeal upheld that judgment. On 2 August 2005 the Supreme Court of Justice quashed the lower courts' judgments and adopted its own judgment, finding B. guilty but absolving him of criminal responsibility because the limitation period for sentencing him had expired.

As the Court has had previous occasion to remark, the concept of "private life" is a broad term not susceptible to exhaustive definition. It covers, inter alia, the physical and psychological integrity of a person (see *X and Y v. the Netherlands*, 26 March 1985, §22, Series A No. 91,

and *Pretty v. the United Kingdom*, No. 2346/02, §61, ECHR 2002 III). In particular, administering medical treatment contrary to the wishes of a patient will interfere with his or her rights under Article 8 of the Convention (see Glass, cited above, §70).

In the present case, the domestic courts found a breach of the first applicant's rights. Even though the courts did not expressly refer to Article 8 of the Convention, they established that there had been a serious interference with the first applicant's physical and psychological integrity in the absence of her knowledge or consent.

The devastating effect on the first applicant from having lost her ability to reproduce and from the ensuing long-term health problems make this a particularly serious interference with her rights under Article 8 of the Convention, requiring sufficient just satisfaction.

In the light of the foregoing, the Court considers that the first applicant has not lost her victim status and that there has been a violation of Article 8 of the Convention.

So, one may see that the Court is ready to consider the medical errors in the context of the breach of Article 8 and assign pecuniary and moral compensation to be paid by the state.

## The study of the national courts' cases in 2012 on protecting the rights of patients

Analyzing the practices of the national courts (using the data from the Single Registry of Courts' Judgments (hereinafter — the Registry), we may summarize the key trends demonstrated by the domestic litigation in 2012.

1. The share of the criminal cases prosecuting the individuals who committed the offenses aimed at breaching the rights of patients is insignificant.

Thus, we identified only 4 convictions in the Registry when the individuals were brought to

liability for committing an offense as prescribed by Article 140 of the Criminal Code of Ukraine (Improper performance of professional duty by a member of medical or pharmaceutical profession). That is remarkable that 3 of 4 verdicts are in fact acquittals, which is an outstanding rare phenomenon for the national judicial practice.

It is noticeable that in all 4 cases death of patients became consequence of the medical malpractice.

Thus, the case No. 1–25\12, within the frame of which Vyshgorod district court adjudicated, included the following circumstances.

On February 11, 2011 without getting a consent from the deputy chief doctor on treatment issues PERSON 4, the chief of the medical department and a practitioner at the therapeutic department for the socially unprotected individuals (the marginalized populations) at Kyiv City Clinical Hospital No. 1 ordered a hospital car "Toyota" and told the following patients to prepare for transportation: PERSON\_7, PERSON\_8, PERSON\_11, PERSON\_6 and PERSON\_10. He also issued an oral instruction to his subordinate staff members PERSON\_12 and PERSON\_13 to help the former, having an intent to transport the mentioned persons outside Kyiv and leave them there with the purpose to free the premises of the therapeutic department for the socially unprotected individuals of Kyiv City Clinical Hospital No. 1 for patients. After PERSON\_7, PERSON\_8, PERSON 11, PERSON 6 and PERSON 10 were placed to the car at around 15:00, PERSON\_4 gave the driver an oral instruction to bring him and the mentioned patients to the town of Vyshgorod, where PERSON\_4 left PERSON\_7, PERSON\_8, PERSON\_11, PERSON\_6 and PER-SON\_10 at the public transport stop located at of one of town streets.

PERSON\_4 was aware that the individuals left by him would not be able to take any measure to save their lives, because the outside air temperature was 0 — +1 degrees C; the patients were left, having no money; PERSON\_7 was a disabled person, because she had her toes of the left foot missing; PERSON\_9 had a pathological impairment of the lower limbs' function, namely, paraplegia with high reflexes, pathological neurology signs and adduction contractures; PERSON\_6 had a toxic encephalopathy with convulsive disorder and impairment of walking function; PERSON\_8 had his right leg amputated up to the medium third of the thigh; PERSON\_10 was inaccessible in terms of communication (productive) contact, had an impairment of left limbs' function. On February 11, 2011 at around 18:00 PERSON\_7, PERSON\_8, PERSON\_11, PERSON\_6 and PERSON\_10 were brought by an ambulance to the admission room of Vyshgorod Central District Hospital where the latter were diagnosed with "general exposure to cold".

On February 11, 2011 at around 22:10 PERSON\_7 died at Vyshgorod Central District Hospital of coronary artery disease. The circumstance of impact of low temperature over this event was not proved in the court's room.

The court's proceedings resulted in finding PERSON\_4 guilty in committing an offence prescribed by Article 135, part 1 of the Criminal Code of Ukraine and was punished by 1 year of imprisonment.

Pursuant to Articles 365, part 3 and Article 140, part 1 of the Criminal Code of Ukraine PERSON\_4 was acquitted.

Within the frame of the case *No. 0110/1844/2012* the person guilty in afflicting the injuries that resulted in death of the victim was found guilty for committing an offense as prescribed by Article 140 of the Criminal Code of Ukraine; however, the person was exempted from responsibility due to the expiry of the term of criminal liability.

The case's circumstances are as follows: PERSON\_2, working as a surgeon of the surgery department of the Territorial Medical Facility, Sudak City Council, on October 25, 2003 at 20-00, being a doctor on duty without a consent by the chief of the surgery department, single-handedly took a decision on conducting a puncture of the soft tissues of upper third of the left shoulder and further surgery intervention to the patient PERSON\_3 who had been admitted to a hospital with a diagnosis "post-injury hematoma of the

left shoulder with injury of vessels and nerves, syndrome of crushing of soft tissues of the left shoulder". The undertaken intervention resulted in an injury of the left inguinal artery, leading to internal bleeding; the aftermath led to the death of the PERSON 3 at around 00:55.

The circumstances of the case No. 1-398/11 are almost identical: the verdict recognized defendant to be innocent of the count as prescribed by Article 140, part 1 of the Criminal Code of Ukraine and acquitted him.

This is the case on poisoning of the patient by lidocaine; the patient was in the state of the expressed intoxication caused by the generalized form of stomach cancer. The anesthesiologist who was observing the patient at the intensive therapy unit of the department of anesthesiology and intensive therapy, Cherkasy Oncology Dispensary, did not take into account the severe condition of the patient and all counter-indications; he administered lidocaine, which resulted in the death of a patient. The cause and effect link between the drug administration and the death of the person was determined by the commission's forensic examination, which constitutes an extraordinary case in judicial practice per se.

2. Availability of positive judgments by the courts regarding satisfaction of the claims on redressing pecuniary or moral damage only if there are severe circumstances in place and/or criminal charges pressed against the person culpable in violating a patient's rights.

Thus, according to the case *No. 1305/2-129/10*, ruled out by the commission of judges of the court's chamber in civil cases of the Court of Appeals, Lviv region, on August 27, 2012 the court presenting the legal position of the court refers to the fact that the person was found guilty in inflicting damage to life and health of the plaintiff was held criminally liable.

According to the case's circumstances, on July 20, 2007 in the course of child delivery by PERSON\_3 at Horodok Central District Hospital (hereinafter — CDH) the intrauterine as-

phyxiation of the foetus occurred; that resulted in severe consequences, namely, in the death of the foetus.

The criminal case evidence determined that the death of the foetus was caused by the fact that PERSON\_6, who worked as the chief of Obstetrician and Gynecology Department, Horodok CDH, while assisting in childbirth, discharged the professional duties improperly due to the negligent attitude to them.

Horodok District Court, Lviv region, ruled out on June 16, 2009, that PERSON\_6 was found guilty in committing the offense as prescribed by Article 140, part 1 of the Criminal Code of Ukraine (Improper performance of professional duty by a member of medical or pharmaceutical profession); however, the person was exempted from criminal liability pursuant to the procedure and the conditions prescribed by Articles 1 and 5, items "g" and "d" of the Law of Ukraine "On Amnesty" of December 12, 2008; the criminal proceedings were closed.

The Court of Appeal issued a quite rare ruling for the national practice: on the need to change the judgment by Horodok District Court, Lviv region as of November 16, 2010, by increasing the amount of compensation for moral (non-pecuniary) damage to be exacted from Horodok Central District Hospital in favor of PERSON\_3 from 30,000 UAH to 80,000 (eighty thousand) UAH.

After studying the text of the judgment we consider the underlying key ground for the court to issue such a judgment was the proved (in the course of criminal proceedings) guilt of the doctor in committing improper performance of professional duty by a member of medical or pharmaceutical profession due to neglect of careless discharge of this duty, which caused grave consequences for a patient — in this case it was the death of the child.

3. The unpreparedness of the courts to satisfy the claims against healthcare facilities

## and doctors culpable for inflicting damage to life and/or life of patients.

According to the Registry, in 2012 27 judgments were issued in civil proceedings regarding the so-called "doctors' cases".

Within 18 of 27 cases the judgments were issued on rejection in satisfying the claim in full; according to 9 cases the courts ruled out on partial or full satisfaction of the claim.

This trend is similar for previous years as well. Despite the growth of the judgments issued on the merits in "medical cases", the courts still follow the practice of the previous years — to reject the claims on redressing pecuniary and/or moral damage in full or partially.

4. Forensic experts' position is often ungrounded in terms of their evaluation of the deeds or inactivity of healthcare providers, the consequences of their deeds and the cause and effect relation between them.

Thus, according to the case *No. 1-25\12* the lack of the cause and effect link between the abandoning several patients in the street under low temperatures by the doctor and further death of one of them the next day is corroborated by the evidence of the forensic expert.

PERSON\_22, the forensic expert, interrogated in a court's session, explained that the death of PERSON 7 was caused by the coronary artery disease with developing coronary insufficiency. The features of the impact of low temperatures over the body of PERSON\_7 are confirmed by the findings of the histologic examination. But he also indicated that PERSON\_7's body had features of frostbite that had occurred long before the death; it is confirmed by the necrosis of the feet. The expert could not explain to what extent the stay of PERSON\_7 under low temperatures a few hours before the death influenced over the fact of death. He explained to the court that the effect of low temperatures is witnessed by the dotted bleedings on the mucous membrane of the kidneys' pelvises: these are macroscopic disorders. Exposure to cold is not the cause of death of PERSON\_7; the coronary artery disease

is. The impact of the low temperature refers to the sphere of probability.

As there were no other evidence to prove the connection of the low temperature's effect and the death of PERSON\_7 submitted for the court's consideration, the court did not determine the cause and effect link between the healthcare provider's acts and the death of the patient. Consequently, the accused was acquitted by the court in compliance with Article 140 of the Criminal Code of Ukraine.

One may observe the similar situation in civil proceedings. Within the frame of the case *No. 2-5428/11* on redressing the damage inflicted to the health, in compliance with the Report by the Commission's examination of the quality of the medical care provided to the patient PERSON\_1 of December 14, 2009, included into the case files (pages 61–62), the post-surgery complications of the plaintiff — osteomyelitis — may be explained by the propensity to this disease due to anatomy and physiology specific features of the lower limbs, namely lack of sufficient muscle tissue, atrophy of muscles, heightened amount of subcutaneous fat cellular tissue.

## $\overline{3}$ Rec

#### Recommendations

- 1. To lawyers: to study more thoroughly the European Court's practices to conceive the logic and case law of the Court in "medical" cases.
- 2. To draw the attention of the lawyers that patients' rights in the European Court of Human Rights may be protected by referring to the breach of Article 8 of the Convention if the process and outcomes of non-delivery and/or insufficient delivery of medical care were not those that could be considered an act of torture and/or inhuman or degrading treatment. In cases when the consequences of non-delivery or insufficient delivery of medical care are more substantial, one should make a reference to the breach of Article 3 of the Convention and request the Court to deem the tort to be an act of torture and/or

degrading treatment or to Article 2 — if the offence resulted in the death of an individual.

- 3. To compile a collection of "medical cases" claims' templates within the frame of civil proceedings at the national level, making reference to the Convention's provisions.
- 4. To draw the attention of lawyers to the need in proper formulation of the claim demands in the course of national litigation indicating not only pecuniary and non-pecuniary damage as claim demands, but to demand recognition of the deeds or failure to act by healthcare providers to be a breach of the law.
- 5. The criminal and civil proceedings' parties should apply alternative examination more

broadly as an additional argument to support the claim.

- 6. To the courts while issuing judgments to take into account the severity of the consequences resulted by the deeds or failure to act by defendants; to study the reports of the forensic examination and the experts' testimony from the perspective of impartiality and respective and validity of the conclusions as well as compliance with the actual case's circumstances.
- 7. To the state expert bodies to make the disciplinary liability system more effective to sanction experts for the low professional performance while conducting an examination, incomplete examination of all circumstances and material evidence.

# THE SPECIAL PART

## Chapter 3

### **HUMAN RIGHTS IN PALLIATIVE AND HOSPICE CARE**

ithin recent years the mortality incidence in Ukraine constitutes 800,000 deaths per year, 90,000 of them die of cancer. Pursuant to the WHO and international experts' recommendations, 60% of them (i.e. around 500,000 patients) at their terminal stages are in need of professional palliative and hospice care<sup>1</sup>.

**Palliative care** is — 1) an integrated approach aimed at ensuring the highest attainable quality of life for palliative patients and their family members through the prevention and relief of suffering by means of early identification and impeccable diagnosing of the pain symptoms and disorders of vital functions, undertaking adequate treatment interventions, symptomatic therapy and care, providing psychological, social, spiritual and moral support irrespective of a patient's disease, age, social status, nationality, religious and political beliefs, place of residence; 2) an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.<sup>2</sup>

Hospice care is — 1) a component of palliative care; it is provided to palliative patients, primarily, at the terminal stage of the disease and their family members by the professionals specifically rained in delivering palliative and hospice care; 2) the care encompassing providing support for the people at the terminal stage of their disease<sup>3</sup>.

## 1)

## Palliative and hospice care in Ukraine in 2012: data analysis

The palliative and hospice care development in Ukraine has been turning more and more problematic in Ukraine from year to year. There are around 3 million persons aged 75+ in the country; most of them suffer from oncology diseases, chronic somatic diseases, degenerative lesions of brain and spinal cord, periphery nervous system and musculoskeletal system as well as other diseases featuring chronic pain syndrome and other severe disorders. These patients need protracted medical and social care as well integrated support. Besides, young people and children also have cancer. They

<sup>&</sup>lt;sup>1</sup> The Chapter has been drafted by Olha Lubyana and Vitaly Kuchynsky.

<sup>&</sup>lt;sup>2</sup> MoH of Ukraine, draft of the Order "On organizing the activities and functioning of "Hospice", a healthcare facility of special type, the department of palliative and hospice medi-

cine and the specialized multidisciplinary palliative care team of 12/10/10.

<sup>&</sup>lt;sup>3</sup> MoH of Ukraine, draft of the Order "On organizing the activities and functioning of "Hospice", a healthcare facility of special type, the department of palliative and hospice medicine and the specialized multidisciplinary palliative care team of 12/10/10.

are also in need of palliative and hospice care at their terminal stages. As of January 1, 2011 more than 5,500 children were registered with oncology facilities. Palliative and hospice care development becomes even more topical with the spread of HIV-infection and AIDS, tuberculosis, hepatitis B and C.

According to the National Cancer Registry, from 30% to 60% of all cancer patients in Ukraine are not provided with specific treatment, which has an impact over the mortality rate, mortality incidence and survival rate.

Around one third of the patients with malignant tumors of digestive system and half of the patients with malignant tumors of respiratory organs are not provided with specific treatment. That is the explanation why 30% — 50% of the patients do not survive for more than one year.

The study of cancer epidemiological situation in Ukraine produced the following findings: the prevalence rate grew in 2010 by 3.8% compared to 2009; age-standardized rates grew by 2.5%, according to reliable sources of information.<sup>4</sup>

Also, according to experts, professional palliative and hospice care is currently provided for less than 10% of terminal patients at in-patient facilities and at their homes, although there is a need to provide it for 1.5 million dying patients and their family members.

"My sister had not slept a wink for three months, groaned incessantly, cried, begged for pain treatment. I won't forget these hands stretched to me until I die. She had a cervical cancer. She consulted doctors very late, too late. First she treated her pain with analgin (metamizole), baralgin, no-spa, ketanol... When the pain became really severe, she consulted a doctor. He referred her to an oncologist. The oncologist told her that it is too late for treatment and prescribed analgesics only... First 2 ampoules of morphine were prescribed, but that was not enough. I approached

4 http://palliative.at.ua

the oncologist and entreated him; he prescribed 4 ampoules... However, the nurse attended us only in the mornings and evenings; she did not come on week-ends whatsoever. It is a long distance to cover to get to our place, and she had a lot of other patients. I asked her to leave the ampoules for me, so that I would administer injections myself, but she was not authorized to do so. I can understand that..."

"The pain appeared around six months ago. It is the pain that made me to consult a doctor. Sometimes the pain abates, sometimes it becomes excruciating. Most often pain appears at nights. I try not to bother by family, but my wife awakes anyway when I start to groan... This pain ruined my life! I wanted to go to the country with my wife, but what country I may dream about! It is so difficult to have a nurse visiting you even here in the city!... The wife asked to increase the dose of the analgesic, but the doctor said it was the highest allowed dose. That is the law."

Most of the doctors think that the highest possible daily dose of morphine hydrochloride is 50 mg as indicated in the instructions on administering the drug. But the WHO recommendations on treating the chronic pain syndrome do not comprise this restriction in using morphine. The misconception on respiratory depression, hallucinations and brain blood flow disorders caused by excessive use of single and daily doses of morphine to the patients with chronic pain syndrome was dispelled by modern medical science long ago. But WHO recommendations are not followed at the territory of Ukraine.

2) The story of a cancer patient from Severodonetsk: a case study of the breach of rights concerning the patients with a chronic pain syndrome

The story of the patient from Severdonetsk (Luhansk region) became one of the illustrative examples how the rights of cancer patients suffering from chronic pain are breached. His family members approached Kharkiv-based NGO "In-

stitute for Strategic Researches and Strategies" after all their previous attempts to help him produced no results.

"My father has cancer, the 4th stage with metastases to the spine; he is bed ridden and needs permanent care. We are administering butorphanol tartate to treat pain; but it disappeared at pharmacies due to the process of re-registration and will appear again on March 15. Other similar medicines do not have an effect over him. The attending doctor refuses to prescribe the drugs containing tramadol, because the drugs obtained in compliance with red prescriptions are allowed to be administered at an in-patient facility only. He refuses to be admitted to an in-patient facility (he wants to die at home); anyway, it is impossible to bring him there without inflicting additional injuries. The father was administered with butorphanol tartate for 8 months; we were purchasing the drug at a pharmacy only in compliance with a doctor's prescriptions".

Also the family members of cancer patients in Luhansk region approached various bodies, particularly, the Ministry of Health of Ukraine; the Chief Department of Healthcare, Luhansk State Administration with a request that they want to be provided with palliative home care (hospital-at-home), including supply of narcotic analgesics — pursuant to the Order of the Ministry of Health of Ukraine No. 11 "On adopting the procedure of handling narcotic drugs, psychotropic substances and precursors at healthcare facilities of Ukraine", Articles 3.10 and 3.11.

The official answer stated that medical care for cancer patients in Severodonetsk did not provide for home care (hospital-at-home) and supply of narcotic analgesics. Also it is remarkable that after 8 month uptake of butorphanol (the drug prescribed to the cancer patient), prescribing of tramadol does not comply with reasonable standards of pain management (WHO Pain Relief Ladder); in other words, tramadol will not have any effect if the pain is quite severe. It is absolutely normal to select pain treatment medicines for a patient, staying at his home. After the patient's son had called the hot line of Luhansk Regional State Administration, the situ-

ation changed. An ambulance started to visit the patient thrice a day. According to the patient, ambulance team members administer an analgesic (morphine) and ask to sign a confirmation on rejection from admission every time. In this case the adequate medical care was restored after 3-week (!) break.

In early 2012 "The Institute for Legal Researches and Strategies" NGO received an answer from the Chief Department of Healthcare, Luhansk State Regional Administration regarding the situation with palliative care in the region. The Chief of the department told about the developed infrastructure of the palliative care service in the region: there are 192 beds in Luhansk region; within 2011 1,407 incurable patients with various nosologies were provided with care. However, it is clear from the text of the answer that the pain treatment rooms were not introduced in the region, constituting a gap in implementation of the Regional Targeted Integrated Healthcare Development Program in Luhansk region for 2011–2014. The justification for this underperformance seems substantial: the Order of the Ministry of Health No. 33 of February 23, 2000 "On standards of staff lists..." does not include a description of staff lists for pain treatment rooms. But the question arises what the reason was to include the provision into the Regional Program if, according to officials, this novelty was not possible whatsoever?

The second important point is about visiting services. The answer to the request states that the Chief Department of Healthcare had not issued any procedures on organizing visiting services to provide home care (hospital-athome) on the grounds of missing respective MoH regulating documents. Thus, this answer may be interpreted in such a way that that there are no hospital-at-home services to be provided by regional healthcare facilities and visiting services do not exist. Also one may draw a conclusion that there are no visiting teams to provide home care services, although their functioning is regulated by the Order No. 11 of MoH of January 21, 2010 "On Adoption...". Hence, we may state that the Order No. 11 of MoH of January 21, 2010 "On Adoption..." is not implemented in the region; patients with moderate and severe pain are not provided with narcotic analgesics if they express a wish to have home care.

The calls to the Hot Line established by Yu. Yanenko Luhansk Regional Charitable Foundation provided evidence that there was a big problem with health care services for patients with incurable diseases in Luhansk region.

Within the mentioned timeframe 581 calls were registered; 260 of them (44.7%) were given on behalf of the patients suffering from incurable diseases and were in need of palliative care as well as support treatment aimed at relieving sufferings.

# Here are some opinions by Luhansk oblast residents on situation with palliative and hospice care in their region:

"The hospice was opened — that's great. However, there are families that bring their patients there. It is quite upsetting to live together with dying people. So, if there is an opportunity to ensure care at home... There is a visiting service for these cases in other cities. This means that a nurse attends a patient two times a day and administers morphine. But they must have "optimized" this service in Severodonetsk after setting up a cancer department. The family members themselves are not able to administer these injections, because morphine's supply through pharmacies is forbidden. It can be done only at in-patient facilities. The consequence is that Severodonetsk patients at their terminal stages suffer from unbearable pain. There are several hundreds of these patients every year. Both authorities and healthcare providers should be punished." "My relatives in Donetsk have the same problem. Morphine is available at the **hospice only.** They were bringing the patient to administer the injections two times per day. So, it is a national problem, not just for the city. It is a challenge to resolve this problem for one city". "But we should not blame a doctor only, which is the tradition. There were times when both tramadol and morphine were prescribed; they were administering morphine at patients' homes, too, but it was 10 years ago. It was so until the moment when bureaucrats started the war on recreational drugs. Do you think a doctor is not willing to prescribe an analgesic?!

There are no problems here. But a doctor is bombarded with authorities' orders on the war against drug addicts; these bureaucrats are concerned lest a doctor follows the wrong way. Of course, these measures did not reduce the number of drug addicts. They find their source of pleasure all right. It is the average people who suffer."

Here is the opinion by Viktor Paramonov, the chief doctor of Cherkasy cancer dispensary:

"For instance, we are approached in rural location with a document that a patient is need in analgesia by narcotic drugs. The patient upon the return stays bed-ridden at his/her home. The district hospital provides a supply of drugs. Somebody has to administer these drugs. There is somebody who is specially called for this purpose. OK, the injection is done at night. What about day time? OK, there are some patients who will endure the pain. But why should not be three injections per day or five ones? Where is it written that there must be just two injections per day? Sometimes I ask the doctors: "What is the maximum number of injections per day?" A long pause... Then they answer: "Three". Why three? — OK, maybe five. — Why five? Maybe twenty-five? — Well, no... — Why? Where is it written that is forbidden? The practitioners erect their internal barriers and that's how these artificial limitations and self-restrictions arise. Just to avoid any troubles..."

## 3 Legislation changes in 2012

Let us try to clarify what the situation should be in compliance with the law. Pursuant to the valid laws and policies of Ukraine, the Ministry of Health of Ukraine's priorities include implementation of state policy aimed at saving lives and health of every citizen, ensuring his/her constitutional right to health care, including professional medical treatment, social care, psychological and spiritual support at the terminal stages of life<sup>5</sup>. This important medical

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<sup>&</sup>lt;sup>5</sup> Minutes of the Official Meeting at the MoH of Ukraine of 04/29/2010 "Hospice and palliative medicine development"-http://www.moz.gov.ua/ua

and social goal may be attained only if efforts of various healthcare facilities and professionals are united; the number of specialized palliative and hospice departments should be increased as well as palliative and hospice beds at cancer and general in-patient facilities; professional home palliative care services' delivery should also be organized.

In 2010–2011 a set of measures were undertaken to improve the policy infrastructure and palliative and hospice care practices. Particularly, in May 2010 the Ministry of Health of Ukraine and the National Academy of Medical Sciences of Ukraine issued a special Order No. 409/36 "On implementation of objectives and activities within the frame of the National Program on Cancer Control for the period up to 2016"; this policy includes activities on development of palliative and hospice care for cancer patients.<sup>6</sup>

While reviewing the developments in palliative and hospice care in 2012, we may witness quite substantial changes that occurred within the year. It won't be an exaggeration if we declare this year to occur under the slogan "Stop pain"; in other words, certain steps were taken to improve the situation with access to pain relief. These steps are primarily associated with improvement of palliative and hospice care policy infrastructure as well as its harmonization with international standards and recommendations. Civil society organizations played a significant role in this process. Let us review these steps in more detail.



### STOPBIL (Stop Pain) campaign

In January 2012 STOPBIL (Stop Pain) campaign was launched with organizational and financial support provided by the Public Health Program, International Renaissance Foundation;

the campaign was aimed at expanding the access to pain management. Within the frame of the campaign during the whole year the activities were undertaken to rapidly change the situation with pain management in Ukraine, particularly the lack of tableted morphine and excessively onerous system of prescribing pain management medicines, which is still operational in our country. The video programs broadcast by Ukrainian TV channels presented a clear evidence of the fact that access to pain management is still a challenge both to patients and their family members. The story told by Lyudmyla Melnyck, Cherkasy is a piece of evidence that the current system of pain management medicines' supply per se pushes people to crime.

"I have to administer an injection, but I have none. I say — Sasha, stand up and come to the restaurant. Buy the drugs [recreational], any drugs, I don't know how".

The nurse comes only at day time. Then it is easier. But at nights they are abandoned to stay with pain face-to-face, when people in white robes do not have their office hours. The law forbids toleave the ampoule with analgesic. If a healthcare provider does not supervise personally the administration of an opioid, that means he will be considered a drug dealer... Both pharmaceutical companies and healthcare bodies' officials face the danger of being associated with drug dealing. Any suggestions on improving care for palliative patients remain unimplemented due to that war on drug addiction."

That is the conclusion drawn by the journalists, Podrobnosti (Details) by Inter TV channel after they had visited just one patient in Cherkasy. There were around 300 cancer patients in that city at their advanced stages in need of potent pain management. There is an epidemic of pain in Ukraine — this thought was covered in many programs, articles and interviews in mass media.

STOPBIL initiated an open letter to the President of Ukraine.

<sup>&</sup>lt;sup>6</sup> The Order of the MoH of Ukraine and the NAMS of Ukraine No. 409/36 of 05/14/2010 "On implementation of objectives and activities within the frame of the National Program on Oncologic Diseases Control for the period up to 2016".

The open letter to the President<sup>7</sup> included a request to urgently adopt the Cabinet of Ministers' Decree "On Adoption of the Procedure of handling narcotic drugs, psychotropic substances and precursors at healthcare facilities". The Decree may substantially ease the life of patients, especially those from distant regions: it entails a provision on an allowed 10-day supply of the drugs to be stored at home; one more provision provides for prescribing a needed drug or increase of the dose by a treating doctor at his/her discretion, no doctors' councils are necessary.

This measure will provide a practitioner with authority. It will be the doctor who will keep a responsibility for prescribing a drug and its dosage. A patient and family members will be warned on their related liability in case on unsolicited use of the prescribed drugs. The draft of the Decree was presented for public discussion; simultaneously the final consultations with related Ministries were being held before submission of the Decree to the Cabinet of Ministers.

On June 26, 2012 within the frame of STOP-BIL campaign the press conference "One minute of pain" was held. It was held on the day the UN General Assembly called the International Day against Drug Abuse and Illicit Trafficking and the International Day in Support of Victims of Torture. In Ukraine we have to proclaim June 26 to be the day of support for terminal patients and their family members, subjected to every day torture under silent consent of authorities.

"Every official who will be authorized to take this decision should take some tea, a kettle, boil some water, pour it into a cup, take this boiling water by your hand and keep just for one minute, and then multiply it by 24 hours".

It is how Dmytro Sherembey, the chair of the charitable foundation, tried to explain the officials the urgency in need of registering tableted morphine in Ukraine.

## (5)

## Legislative changes in 2012. Adapted clinical guidelines

On April 24, 2012 a very significant step was made to improve the situation with pain management in Ukraine — the Ministry of Health of Ukraine drafted the Order No. 311 **On adoption and implementation of medical and technology documents on standards of palliative medical care in cases of chronic pain syndrome.** This Order introduces the standard of care for the patients with chronic pain syndrome.

On May 28, 2012 the Ministry of Health sent out this Order to the regional Departments of Health.

The adapted clinical guideline on pain control attached to Order No. 311 defines three-step WHO analgesic ladder.<sup>8</sup>

Pursuant to WHO and IAPHC recommendations (2008), there are three core levels of pain management in cases of chronic pain syndrome cancer patients experience:

Step 1 — *mild pain* — non-narcotic analgesics and non-steroidal anti-flammatory drugs with analgesic effect are prescribed; if there is a need, adjuvants are added to strengthen the effect of analgesics and control other symptoms of the disease, in particular sedatives.

**Step 2** — if there is a *moderate pain*, and nonnarcotic drugs' prescription is insufficient, the 1 step drugs are added with **weak opioids** and the above mentioned adjuvants.

<sup>&</sup>lt;sup>7</sup> http://stopbil.in.ua/

<sup>&</sup>lt;sup>8</sup> MoH of Ukraine, Order No. 311 of 24 April, 2012, "On adoption and implementation of medical and technology documents on standards of palliative medical care in cases of chronic pain syndrome", — p. 70.

**Step 3** — if there is a **severe and breakthrough pain** and Step 1 and Step 2 drugs do not have an effect, one must prescribe **strong opioids (morphine group),** however, non-narcotic analgesics and adjuvants should not be secluded. The doses of opioid analgesics are gradually titrated **upward** (from lower dose to higher dose) until the necessary pharmacological and treatment effect is achieved.

The Guidelines also include tables of maximum daily doses for primary healthcare centers. The maximum daily dose of morphine is 200 mg: in contrast to maximum of 50 mg dose before the Order was adopted.

Thus, Order No. 311 has become a considerable step in the direction of securing the key objective of civil society organizations' advocacy campaigns — to guarantee the accessibility of adequate treatment, including by opioid analgesics, by the government.

However, there are still a lot of unresolved issues. One of these issues is that there is no tableted (oral) morphine in Ukraine.

## **(6)**

#### **Human rights NGOs report**

"We have the right to live without pain and sufferings" report (the human rights NGOs report on palliative patients' rights in Ukraine)<sup>9</sup> drafted by Kharkiv Institute for Legal Researches and Strategies identifies the key problems related to the lack of tableted morphine in Ukraine. This report includes testimony by patients, their relatives, chiefs of healthcare facilities, health practitioners, social workers; these pieces of testimony were collected by the human rights

NGOs activists in Kharkiv, Rivne and Simpheropil in 2009–2012. Human Rights Watch took part in the survey<sup>10</sup>; its involvement made it possible to look at the problem without partiality and take into account international differences.

It is known that oral morphine is included into the WHO Model List of Essential Medicines. The first WHO principle on treating chronic pain is based upon it: if there is an opportunity, opioid analgesics should be prescribed in oral formulations (tablet or syrup). Ukraine does not have tableted morphine yet. It constitutes almost the most important problem, interfering with the access of palliative patients to analgesics. The point is that in compliance with the valid legislation of Ukraine, only healthcare practitioners are authorized to prescribe injectable formulations of morphine; the used ampoules are strictly accountable. Healthcare professionals are not entitled to leave the injectable morphine at patients' homes.

On the other hand, the valid legislation of Ukraine does not forbid the patients to purchase tableted morphine at pharmacies according to prescriptions; however, the tableted formulation is not present at pharmaceutical market of Ukraine.

This situation leads to the breach of the second WHO recommendation on treatment of chronic pain: analgesics should be administered "around the clock", i. e. in some fixed periods of time (4 hours); this principle reflects the analgesic effect of morphine that lasts around 4 hours.

As it is pretty clear, a healthcare professional is not in the position to attend a patient every four hours within 24 hours. Therefore, in reality injections are administered two times per 24 hours — in the morning and before bedtime. Thus, patients can live without pain and sufferings for 8 hours only. And even this regime is possible for the patients living near healthcare facilities. The patients living in distant places, in

<sup>&</sup>lt;sup>9</sup> "We have the right to live without pain and sufferings": the human rights NGOs report on palliative patients' rights in Ukraine / [A. Rokhansky, A. Kotenko, Yu. Lazarevich, Ye. Baborykin, Ye. Druzhinina]: edited by. O.Lubyana. — K.: Kalita publiching house, 2012.

<sup>&</sup>lt;sup>10</sup> Human Right Watch, 350 Fifth Avenue, 34<sup>th</sup> floor, New York, NY 10118-3299 USA, hrwnyc@hrw.org.

rural regions, most often are not provided with opioid analgesics whatsoever.

That is highly topical for rural residents, because there is no visiting nurse service in many rural districts. Very often palliative patients in rural regions are not provided with opioid analgesics at all.

One more huge problem, which was widely covered for attention of the international community at XVIII International AIDS Conference Vienna, 18-23 July 2010, is a critical condition of the patients living with HIV who suffer from pain. The stigma often prevents these patients from using opioid analgesics to control pain, disregarding the valid clinical guidelines.<sup>11</sup>

Within the frame of prohibition of torture and degrading treatment the government of Ukraine has a positive commitment to protect any individuals within its jurisdiction from inhuman or degrading treatment, including from unjustified sufferings caused by acute pain. As the pain treatment methods suggested by Ukrainian state healthcare system are in discrepancy with the recognized international practice, and the Government has not undertaken respective measures to fix the problem, that may be interpreted as a breach of the prohibition of torture, inhuman and degrading treatment. <sup>12</sup>

«...it became clear that the pain will stay with me for long. The combination of tableted short release morphine and morphine retard was prescribed to me. I was to take morphine with extended release 2 times per day, strictly by hours. If I felt pain in the intermissions between these uptakes, I could take short release morphine with rapid effect. And... the LIFE returned to me! I took a tablet in the morning and went for a walk. I danced in the central square in my wheelchair. I worked, I solved dozens of problems, I LIVED! Only when I forgot myself in the whirlwind of affairs and did not take my analgesic, I remem-

<sup>11</sup> MoH of Ukraine "Clinical guidelines on delivery of palliative care, symptomatic and pathogenic treatment for HIV patients" No. 368 of 07/03/2007

bered that I had pain... morphine pain...I ran to gulp my dose, and in an hour I returned to my normal self again — laughing, working, chatting with friends, I was just an average human!!! It was just like a magic!" — these are the words by Iryna Havrysheva, who knows from her own experience — how it is important to provide a human being with an opportunity to LIVE even if one's life expectancy term is limited. Quite the opposite, it is very important to prevent the pain from stopping the life in these last days.

Here is the testimony by Gillian Burn, British nurse, WHO officer, who visits problematic regions and helps with organizing palliative and hospice care.

«Despite all initial fears, now morphine may be used in India at home. Gradually people start to realize: patients do not develop dependency from morphine. One should understand the purpose for patients' use of this drug. They want to get rid of pain. They want to return to normal life: to communicate with children, have walks, work, have a rest. Dependent people use injections to switch off the normal life. Here is the difference. And it is not possible to get high on oral morphine".

### 7 The Draft Decree on adopting the procedure of handling narcotic drugs

The WHO recommendations on medical use of morphine are universally recognized and evidence-based. The Government's objective is to ensure the balance between prevention of their leaking out into unsolicited use and the sufficient availability and accessibility of opioid analgesics for adequate pain treatment with terminal patients. Therefore, the urgent approval of the Decree "On adoption of the Procedure of handling narcotic drugs, psychotropic substances and precursors at healthcare facilities" becomes so important. Human rights NGOs advocated for its adoption in their letter to the President of Ukraine; the draft was repeatedly discussed and agreed and

<sup>&</sup>lt;sup>12</sup> Human Rights Watch report "Uncontrolled Pain. Ukraine's Obligation to Ensure Evidence-Based Palliative Care", May 2011, p.16.

now is submitted for consideration of the Cabinet of Ministers of Ukraine.

The Decree makes these essential medicines more accessible for patients.

Strengthening of the policy framework — the steps that already occurred and future ones — is the guarantee of Ukraine's new vision of palliative patients' rights in the context of human rights and fundamental principles of healthcare from the perspective of Ukraine's international commitments. These steps are supposed to crucially change the situation in this sphere.

### (8)

#### Recommendations

- 1. To most urgently adopt the Decree "On adoption of the Procedure of handling narcotic drugs, psychotropic substances and precursors at healthcare facilities" as the one restoring human rights in health care and to introduce respective amendments into the MoH orders as well as into the policies by other Ministries and agencies.
- 2. To ensure availability of oral (tableted) morphine at the pharmaceutical market of Ukraine. To include oral morphine into the list of the medicines procured with the funds allocated from the national budget, which is sup-

posed to present incentives for importation or domestic production.

- 3. To simplify the procedure of getting a license to deal with narcotic drugs for healthcare facilities and pharmacies.
- 4. To ensure the most urgent issuance of licenses to handle narcotic drugs for the newly-created healthcare facilities (Emergency Medical Care Centers), especially in pilot regions
- 5. To adopt the "National Palliative and Hospice Care Development Program in Ukraine" as a Law of Ukraine and allocate government funding for implementation of this program in the format of the Decree of the Cabinet of Ministers of Ukraine. To consider an opportunity to entitle benefits for companies funding palliative care facilities (hospices), including for insurance companies, private and state-run.
- 6. To introduce "Palliative care" and "WHO analgesic ladder-based chronic pain syndrome management" disciplines into curricula of medical universities.
- 7. To set up expert training centers at hospices for specialized training and continuing education for doctors and nurses working in the sphere of palliative care.
- 8. To develop the home palliative care system by means of developing the visiting nurses' services at regular clinics in terms of transforming them from the narcotic drugs delivery service into a visiting multidisciplinary palliative care service.

### Chapter 4

# THE RIGHTS OF THE PEOPLE LIVING WITH HIV/AIDS Spotlight. Chronicles of struggle

# 1 The State Penitentiary Service opened doors for civil society organizations of Ukraine

On March 28, 2012 the All-Ukrainian Network of the people living with HIV/AIDS and the State Penitentiary Service of Ukraine signed an agreement on cooperation. Volodymyr Zhovtyak, the Chair of the Network's Coordination Council and Serhiy Sydorenko, the First Deputy Head of the Service, solemnly signed and exchanged the copies of the agreement; its provisions include a set of joint activities within the frame of implementing the Global Fund against AIDS, Tuberculosis and Malaria program, Round 10. In general terms, the Agreement entails a range of common efforts to be undertaken by the partners to provide a full range of services on HIV prevention, treatment and support targeting the prison inmates living with HIV2.

The comprehensive access to prevention, treatment, care and support for prison inmates was recognized to be one of the priorities within the frame of the National Program. The cooperation of the Network and the Service will be focused on stabilization of epidemiological situation with HIV/AIDS and the decrease in prevalence and mortality rates at correctional

facilities. In particular, it is planned to procure almost 100,000 testing systems to undertake a large-scale national HIV testing at correctional facilities by the end of 2013. All the patients detected within the frame of these activities will have an access to care and support services at their places of imprisonment: tentative 6,000 persons will be provided with these services. No less important is the fact that the issue of access of inmates to antiretroviral therapy was allocated with special attention within the project.

"Signing of this agreement is not only a significant step forward in cooperation between the PLWH Network and the State Penitentiary Service, but an incredible breakthrough in combatting HIV/AIDS epidemic in Ukraine. Our cooperation is primarily focused on reducing the speed of the epidemic's growth at penitentiary settings. We, being the partners in implementation of the Global Fund Project (Round 10) will undertake maximum efforts to make sure that every person living HIV/AIDS who stays in closed settings will have an access to the complete set of services on treatment, care and support, so that these patients will be able to enjoy full-fledged life" — Volodymyr Zhovtyak, the Chair of the Coordination Council of the All-Ukrainian Network of the people living with HIV, noted.

<sup>&</sup>lt;sup>1</sup> The Chapter has been drafted by Mykola Kholtobin.

<sup>&</sup>lt;sup>2</sup> http://network.org.ua/media/news/page-2757/



April 25, 2012. "Violence and fabrication of criminal cases against sex workers — these are ones of key strategies by the law enforcement in view of EURO 2012"

Was the message proclaimed by the press conference participants at UNIAN. The press conference was dedicated to the national specific features of police war against sex work in view of European football tournament.

According to the informal rating of the key violence agents compiled by sex workers themselves, police officers were ranked the second (38%) right after clients.

- told a slender girl, Marina, 30; currently she is in danger of being punished with up to 7 years of imprisonment.
- Nataliya, 25, reported. Her confessions were beaten out of her in the direct sense of the word by the Criminal Code as an instrument of torture at one of the police stations of notorious Shevchenko District Office of Kyiv Police Department.
- Denys Ovcharov, the lawyer, said.
   He is an attorney of Maryna accused in pimping.

During the press conference the girls had to cover their faces with masks, because they had grounds to be apprehensive of possible retaliation of the corrupted police officers and the influential pimp who bribed the police and stayed free.

«Bearing in mind the serious character of the case and preventing probable violence applied to the girls, we had to provide them with temporary shelter in the other city area where it will be more difficult to find them. We also forbade them to use their mobile phones. Now we mostly hope for rapid reaction by the Prosecutor's Office and even more — for the coverage by Ukrainian and international mass media who will be monitoring the development of events", — Pavlo Skala, Senior Police and Advocacy Officer, the International HIV/AIDS Alliance, reported.

Olena Tsukerman, the leader of the Legalife, the only NGO in Ukraine, representing the interests of sex workers, confirmed the systematic character of the problems re fabricating the cases and violence committed by the police and affecting sex workers. She did so in her video address from Berlin:

«We condemn use of any methods and instruments the police uses to fabricate cases against sex workers, to extort money, and to apply physical, psychological and sexual violence without being punished. Legalife League calls for investigation and punishment for these crimes, corruption of the police and advocates for review of policies and laws in the sphere of sex work with active involvement of sex workers' community into the process of the reform. Their involvement is crucial because their health and lives directly depend on solution of these problems."

The International HIV/AIDS Alliance in Ukraine also informs about the danger that the further consistent police pressure and misconduct towards sex workers creates for public health: it is for the fourth consecutive year that the sexual intercourse HIV transmission route has remained the dominant one (49% of all registered cases of HIV infection).

According to experts, the number of sex workers in Ukraine is estimated in the range from 52,000 to 83,000. Dnipropetrovsk, Odesa, Donetsk regions, the city of Kyiv and Crimea feature the biggest numbers. It is in these regions that the situation with HIV spread is the most critical one.

According to the recent comprehensive survey (the sample was around 5,000 sex workers), almost 9% of sex workers were living with HIV; the prevalence in Kyiv was almost 24%, in Donetsk — 38%, in Lviv — only 6%.

"If someone surmises that repressive methods as well as other "novelties" applied by the law enforcement will help them to overcome the most ancient occupation and to isolate the girls involved into prostitution from the outside world, in particular before European football tournament 2012, similarly to the methods applied before the Olympic Games when the girls were deported from the capital to the distance of 101 km — it is an ungrounded illusion and a gross error. Both history and reality give the evidence that these strategies will contribute to escalation of violence and corruption, application of more risky practices of delivering sex services, and, as a consequence, to the growth of HIV and other sexually transmitted diseases' prevalence. Are our citizens willing to be ranked "the European first "in this area further on?», — Pavlo Skala's rhetorical question sounded in summary of the press conference<sup>3</sup>.

## 3

# International AIDS Candlelight Memorial. Ukraine HIV positive community calls: "It's time for action!"

The International AIDS Candlelight Memorial is commemorated on the third Sunday of May throughout the world. This year it is May 20.4

The All-Ukrainian Network of the People Living with HIV together with its partners honors the memory of the people who died of this disease. Various actions are planned in all regions of Ukraine.

Kyiv's central event is the solemn ceremony near the "Red Ribbon" monument symbolizing our memory about the people whose lives were purloined by the disease. Representatives of Ukrainian and international civil society and charitable organizations, high profile officials involved in combatting HIV/AIDS in Ukraine, the Ambassadors of the leading countries, show business celebrities were invited to take part. The ceremony was scheduled to start at 10:30 in 11 Lavrska Street.

The memory about the deceased patients means, first of all, the care for those who live as well as preventing the deaths in future.

Since the government recognized the HIV/AIDS epidemic in Ukraine, there have been colossal efforts undertaken in Ukraine and enormous funds have been spent to control it. Ukraine received \$340 million just from one donor — the Global Fund against AIDS, TB and Malaria. Besides, incredible efforts were taken by researchers, healthcare professionals, social workers, civil society organizations' staff and volunteers. It is of paramount importance now not to lose these gains! The government's underfunding for the National HIV/AIDS Program endangers all the positive results.

## It is a high time to control the epidemic now:

- To allocate the full funding for the National HIV/AIDS Program for 2013 to the tune of 923 mln UAH (including 399 mln UAH for treatment).
- To ensure procurement and uninterrupted supply of medicines for PLWH.
- To save the lives of 92,000 Ukrainians who need treatment.
- To ensure full funding from the local budgets (HIV testing, treatment of opportunistic infections, maintenance of the system of providing healthcare services for PLWH).
- To improve the coordination with the international donors and civil society organizations both at the national and the local levels.

One should say that every Ukrainian citizen bears his/her own share of responsibility. First of all, it means a safe lifestyle and awareness about HIV/AIDS.

## 4

## The National HIV/AIDS Advocacy Plan for 2012 has been developed and presented<sup>5</sup>

06/07/2012

Within the frame of "Improving HIV service in Ukraine" project funded by the All-Ukrainian

<sup>&</sup>lt;sup>3</sup> http://www.aidsalliance.org.ua/ru/news/pdf/prap12/ Press\_release\_25%2004%202012\_FSW\_UNIAN.pdf

<sup>&</sup>lt;sup>4</sup> http://network.org.ua/media/news/page-2781/

<sup>&</sup>lt;sup>5</sup> http://network.org.ua/media/news/2012-2/

Network of the people living with HIV supported by the Global Fund, the Coalition of HIV service organizations coordinates advocacy efforts in the sphere of HIV/AIDS control at the national and regional levels.

Since 2008 these efforts have entailed annual planning of the national advocacy activities (taking into account the regional advocacy needs). The Coalition of the HIV service NGOs in partnership with the All-Ukrainian Network of the People living with HIV, the International HIV/AIDS Alliance, Social Initiatives on Labor and Health Protection, "Podolannya (Overcoming)" all-Ukrainian movement of former prison inmates, Gay Forum of Ukraine, the Association of the OST participants of Ukraine, Ukrainian Community Advisory Board and other organizations undertake the planning sessions for further efficient coordinated advocacy interventions with common goals and objectives. The sessions result in designing the annual National Advocacy Plans.

### 5 Today the official was defending his billions near the Parliament<sup>6</sup>

Today, in the framework of 'MP altruist' campaign, the activists gathered near the Verkhovna Rada and proposed to give away 1 billion hryvnias, or the third part of the sum annually assigned for sanatorium-and-spa treatment of state officials, to fatally diseased Ukrainians. A person wearing a business suit of an official tried to protect the billions of artificial hryvnias from fatally diseased patients by trundling them on a handcart in front of the Rada. "Stop hurling around empty promises about dropping MP privileges and benefits", asserts Dmytro Sherembey, an HIV positive, the Head of the Ukrainian Community Advisory Board. "Today we have passed the letters from our patients to MPs, telling them to publicly relinquish one

third of their medical expenses assigned for them and officially sign the abdication. Then the Ministry of Finance will have a chance to assign this money in next year budget for treatment of hepatitis, tuberculosis and AIDS and therefore stop these epidemics in Ukraine. Such altruistic act would reveal most efficiently who of the elected representatives cares about the destiny of people in need and make a choice between the sanatorium vacation for officials and life of thousands of ill Ukrainians".

The State Budget 2012, allocated **UAH 2.6 billion** for treatment and sanatorium-and-spa recreation of departments of the Verkhovna Rada, the Cabinet, the President's Administration, the Ministry of Internal Affairs, and the Ministry of Defense.

Approximately the same sum of money has been allocated by the Ministry of Healthcare for the rest of other Ukrainians for healthcare at regular healthcare facilities (hospitals, polyclinics, medical centers, and first-aid stations) — **UAH 2.8 billion**.

These are the people's deputies who are authorized to cut costs for medical services and sanatorium-and-spa treatment of the state machinery in our country.

The patients' relatives and people who lost their natives due to lack of finance of medical establishments also rallied near the Parliament.

"My son Oleksandr was 38 years old when he was diagnosed with pneumonia. It's probably been a cold caught at work", told us the mother of the deceased Oleksandr. It turned out further that he had tuberculosis. And that was it. It was his death sentence. He was sent to Mostysche, which is called a deadly place. Now I understand why. I sold one room in my apartment in order to save my poor son who was assigned by the government only UAH 3.5 per day. Doctor visited him once a week... But I failed to. I did not make in time. I ran out of money. And now my son is no longer here. However, I have come here today to help other mothers, wives, children save their moms, husbands only because the government does not care, since officials neither see nor hear this staying at their palaces".

<sup>&</sup>lt;sup>6</sup> http://network.org.ua/media/news/page-2965/ and http://www.aidsalliance.org.ua/ua/news/pdf/20.06.2012/Release-20.06\_ukr.doc

"How many voters have you killed?", I put this question to every people's deputy. "There are UAH 2.6 billion on the scales, which are spent today from the state budget for VIP medical services for the authorities and the life of over 4 million Ukrainians living with AIDS, tuberculosis and hepatitis who are still waiting for financing. Even a partial refusal from these privileges can save the life of Ukrainians with life-threatening diseases, you decide!», Director of International HIV/AIDS Alliance in Ukraine Andriy Klepikov appeals to MPs.

"Not a penny has ever been spent from the budget over the entire history of Ukraine for treatment of hepatitis that has affected today 3.5 million Ukrainians. People who should have been provided with free medical services by the government under the Constitution were left to die. I hope that owing to this campaign we will manage to open the eyes of state officials to the issue of financing in Ukraine and first of all for the treatment of such patients", states the Head of the All-Ukrainian Association "Stop Hepatitis" Olga Gavrilova.

The activists handed over books for collect the signatures to the heads of parliamentary factions. Signatures of the deputies will certify their readiness to vote for the State Budget 2013, which would allocate a billion of hryvnias to overcome three epidemics.

"It may be said without exaggeration that epidemics of HIV/AIDS, tuberculosis and viral hepatitis is a kind of a test for our society. This is a test for the government in terms of its ability to get mobilized together with public and international organizations to stop the epidemics. This is a very sensitive indicator, which builds up the country image. That is why taking these three epidemics under control at the modern stage of development of Ukraine is extremely important for the future of our nation", says Volodymyr Zhovtyak, the Head of the Coordination Council of the All-Ukrainian Charity Organization "All-Ukrainian Network of People Living with HIV".



## The XIXth HIV/AIDS Conference started in Washington<sup>7</sup>

On July 22, 2012 the XIXth Interational AIDS Conference commenced in Washington. It is supposed to become one of the key events in 2012 in healthcare and HIV in the world. The Conference will be attended by around 25,000 participants from 195 countries. The Conference's message: "Turning the tide together". HIV prevention will be in the focus of the Conference. New drugs, testing and search for a vaccine will be discussed at the workshops and panel discussions attended by researchers, doctors, decision-makers and people living with HIV. As the economic downturn is still observed in the world, the conference participants will also discuss new ways to finance the HIV/AIDS control activities. According to the participants, that won't be easy, because currently both US and other countries struggle with financial problems.

The All-Ukrainian Network of the People living with HIV will proclaim a slogan "In donors we trust" at the conference. "The operations of such a powerful organization as the Network are endangered now due to the global financial crisis and cuts of the expenses for addressing social problems" — says Volodymyr Zhovtyak, the head of the organization's delegation, the Chair of the Coordination Council of the All-Ukrainian Network of the People Living with HIV, the President of the EECA Network. "We have the experience and know how to stop the epidemic. The only thing we need is a sufficient funding. If we don't have funding, the programs will not be implemented; if the programs are not implemented, there will be no treatment for the people living with HIV; if there is no treatment, all our previous efforts will be wasted!" Even before the Conference started, the researchers commenced to proclaim that the turning point was reached in the war against the virus. On the eve of the conference the US researchers confirmed that ART may be used a prevention tool. Some healthcare professionals think that Washington Conference will be the place to speak about the first steps to end the HIV epidemic.

<sup>&</sup>lt;sup>7</sup> http://www.aids2012.org/



# Ukraine proclaimed at the XIXth International AIDS Conference: IN DONORS WE TRUST!8

More than 10% of Ukrainians have hepatitis virus and demand affordable treatment from the government.<sup>9</sup>

On July 27–30, 2012 within the frame of "We demand treatment!" campaign awareness raising and prevention focused actions were held in Kyiv and in 36 other cities of Ukraine; the action was dedicated to the World Hepatitis Day. All who wished could take a rapid hepatitis test and learn more about diagnostics and treatment of viral hepatitis. The campaign also included press conferences, actions, flash mobs and projects on building a tolerant attitude to marginalized groups using "the live library" approach. 47 partner organizations are involved in the campaign in various regions of Ukraine.

2,326 people were HCV and HBV tested throughout Ukraine. 249 were tested positive, 215 — HCV and 32 — viral HBV.

The biggest share of the people infected with hepatitis among all those who were tested is observed in Pavlohrad (Dnipropetrovsk Oblast) — 35.5%; Vasylkiv (Kyiv oblast) — 20.5%; Makyivka (Donetsk oblast) — 19.3%; Dnipropetrovsk — 18.7%; Donetsk and Sumy — 16.5%. The share of the positive results in Kyiv is 7.7%. The majority of the sample participants were aged 15–55, i. e. the population group able to work.

Ukraine does not have a register of the people living with hepatitis B and C; it does not allocate funds for targeted programs on prevention, affordable testing and treatment. According to World Health Organization's experts, Ukraine is ranked first in Europe in terms of growth of HCV and HBV: there are 3,500,000 patients infected with hepatitis B and C in Ukraine.

The limited competition (only two pharmaceutical companies have the rights to produce the medicines to treat hepatitis) contributes to the high cost of the treatment course. In Ukraine it exceeds \$20,000: the sum unaffordable for most of Ukrainians.

More than 6,000 people signed the petition to the Prime Minister of Ukraine with a demand to recognize the epidemic of viral hepatitis C in the country; to adopt the National Strategy on viral hepatitis control; to develop and adopt the clinical guidelines to treat viral hepatitis in compliance with the international standards; and to ensure government funding for procurement of quality and safe medicines, undertaking measures to reduce the medicines' price at least by 50%.

The action organizers call out to all patients diagnosed with hepatitis B and C to write a personal request with a demand of an affordable treatment to their respective regional healthcare department (we ask to inform the action organizers about the submitted requests at the Facebook account). Now only the number of submitted personal requests may serve as a signal to the MoH on the current prevalence rate and the need in treatment, which is necessary for procurement by the national and local budgets.



### The Case of Mr. Podolyan, MD

On August 16, 2012 the Court of Cassations dismissed the motion by the Prosecutor and finally confirmed that there had been no grounds to accuse Illya Podolyan, a practitioner from Odesa; he was accused in supplying the narcotic drugs to OST patients<sup>10</sup>.

The Council of the Court's Chamber in criminal proceedings, the Supreme Specialized Court of Ukraine, upon consideration of the cassation filed by the Prosecutor regarding the judgment

<sup>&</sup>lt;sup>8</sup> Today, on 07/25/2012, the Ukrainian delegation from the PLWH Network have drawn the attention of the potential donors to the NGO and to Ukraine in general.

<sup>&</sup>lt;sup>9</sup> http://www.aidsalliance.org.ua/cgi-bin/index.cgi?url=/ua/news/2012/index.htm

<sup>&</sup>lt;sup>10</sup> http://www.aidsalliance.org.ua/cgi-bin/index.cgi?url=/ua/news/2012/index.htm

by the Court of Appeals of Odesa region regarding the ruling issued by Kyivsky district court, Odesa of June 29, 2011, turned down the cassation and proclaimed the previous judgments of the courts to be valid and intact.

We remind that earlier the trial court and the court of appeals acquitted Illya Podolyan, the opioid substitution treatment doctor, and recognized the charges against to be ungrounded; the charges were concerned with his alleged numerous facts of supply of OST drugs for more than 40 drug dependent patients provided with treatment at Odesa Regional Drug Treatment Dispensary.

The Supreme Court recognized the prosecutor's complaint and the charge against 64-year-old physician on his alleged drug dealing to be ungrounded. By this it ended the story that had been developing in courts and in investigations for more than two years; it started in March 2010 from detention of Mr. Podolyan, MD, OST program nurses, and the Alliance-Ukraine coordinator, by Odesa police, the arrest of OST medicines and three day interval in treatment for almost 200 program drug dependent patients.

This was the first, and, fortunately, the only case when the OST treatment was stopped for such long term and for so many people. The case resulted in community mobilization — both that of patients and healthcare professionals against the police arbitrary actions.

It was a matter of honor not only for Mr. Podolyan, MD, who was kept in custody for 120 days at Odesa pre-trial detention center, but also for the Alliance-Ukraine as the body implementing the National HIV/AIDS Control Program (OST program component) — to prove in court's room that the charges were ungrounded. And this objective was reached thanks to the courage and uncompromising stand of Illya Kostyantynovych himself, professionalism and hard work of his attorneys and the permanent support by the Alliance.

We initiated a public campaign to protect the doctor: dozens of international and Ukrainian organizations, hundreds of HIV/AIDS and drug

treatment professionals joined us; the case's developments were frequently covered at the international conferences and in mass media.

This recent important victory in court's room gives us the hope to believe that in future similar ungrounded criminal persecutions of OST programs' healthcare staff will be impossible in Ukraine and that the Government will not allow any more shameful incidents like this, especially taking into account the recent legislative support for further scale-up of OST programs in Ukraine.

9

11/29/2012. The International HIV/AIDS Alliance Statement on occasion of the International AIDS Day<sup>11</sup>

Due to inadequate state funding, Ukrainians living with HIV are more likely to die from AIDS than Africans living with HIV who live in countries with the highest HIV burden.

Currently AIDS-related deaths fell by more than 25% between 2005 and 2011 globally. In some countries in sub-Saharan Africa, where HIV has the strongest grip, the decrease was as much as 31%. However, during the same period, the number of AIDS-related deaths in Ukraine grew by a massive 70%.

**There are three reasons** why Ukrainians are more at risk:

**1. Lack of state funding** to tackle the full scale of the HIV epidemic and provide the necessary prevention, treatment and care programs. Every year the state budget only covers 50% of the National HIV/AIDS Response Program. And yet, every day in Ukraine 57 people are newly diagnosed with HIV and 11 people die due to AIDS-related causes.

2013 will be the final year of the five year National HIV/AIDS Response Program. If we are to stand any chance of tackling AIDS and reducing

<sup>&</sup>lt;sup>11</sup> http://www.aidsalliance.org.ua/ru/news/pdf/oplet1112/ Alliance%20Statement\_1%20december\_ukr.pdf

HIV infections, the Ukrainian government must fully fund this Program.

2. Inadequate HIV testing and limited access to antiretroviral therapy (ART) increases AIDS mortality and accelerates the spread of HIV. Only 22% of those who need treatment actually receive it. People who use drugs are six times less likely to obtain treatment compared to an adult who does not use drugs. Considering the fact that the HIV epidemic in Ukraine has historically been driven by injecting drug use, their poor access to treatment threatens the possibility of any further reduction of the HIV epidemic in Ukraine.

In order to increase access to ART for those in urgent need, the artificial barriers should be removed for HIV infection and tuberculosis treatment, as well as substitution maintenance therapy for people who use drugs. According to the National Program, 20,000 people who use drugs must receive the substitution maintenance therapy till the end of 2013 at the state budget expense. In its turn Alliance Ukraine, through cooperation with NGOs, plans to increase to ART treatment access for vulnerable groups to ART by 2.5 times!

3. Neglecting best practices in HIV prevention programs in Ukraine and the creation of barriers that impede implementation are hampering the response. Ukrainian HIV prevention programs implemented by non-governmental organizations in cooperation with healthcare services are recognized as among the best in the world. The Global Fund to Fight AIDS, Tuberculosis and Malaria, one of the world's biggest donors when it comes to HIV, recently highlighted the work of Alliance Ukraine to demonstrate the efficiency of prevention programs among drug users, one of the most vulnerable groups at risk of the epidemic.

Ahead of World AIDS Day on 1 December we call on the President of Ukraine, the Government of Ukraine and the Verkhovna Rada of Ukraine to take immediate action to ensure a full scale national response to the HIV epidemic in Ukraine by:

- Removing barriers for the implementation of the prevention and treatment programs for vulnerable groups including people who inject drugs, men who have sex with men and sex workers;
- Allocating in full the funds planned for implementation of the National HIV/AIDS Response Program in 2013.



### Advocacy

The findings of the survey conducted by the PLWH Network in 2010 testify to the fact that stigmatization, discrimination and abuse of the rights of the people living with HIV/AIDS are frequent in Ukraine. Within 12 months preceding the survey half of the PLWH respondents (51%) had experienced stigmatization and discrimination by other people on the grounds that included their HIV status. Mostly these are gossiping (30%), oral abuse (18%), psychological pressure by a spouse/partner (12%). The shares of PLWH who were physical persecuted due to their HIV status (6%), were not allowed to tackle home affairs (4%), were not allowed to participate In various gatherings (3%) or religious events (2%) are much smaller.

 Advocating for the right to social and health care for the prison inmates and released inmates living with HIV, drug dependent, and TB patients

One should note that the legislation of Ukraine, apart from the general rights and freedoms, provide former prison inmates with additional guarantees to realize their rights, first of all, to be immediately granted with support by the executive power bodies within six months after their release (i. e. within the period of adaption), particularly: support to ensure adequate living conditions, re-training, ID documents (if they are lost), health care, social care and other types of assistance (pursuant to the Law "On social adaptation of the individuals who served their terms,

being punished by the restriction of liberty or imprisonment for a certain term").

However, in reality most of the rights guaranteed by the Constitution and other law for former prison inmates are not respected; the social support measures are not undertaken. The underlying reasons are as follows:

- Low awareness of former prison inmates about the services they are entitled to get from the government bodies and institutions as well as disbelief that the country still "needs" them,
- Low motivation of the government bodies to implement their duties in terms of providing social support services for the individuals released from the places of imprisonment;
- Lack of efficient public control as well media attention over the government bodies' performance re implementing social policy for the former prison inmates.

The inefficient social interventions targeting former prison inmates result in the high share of repeated crimes and the inmates' return to correctional facilities. According to the statistics, around 30% of former prison inmates commit repeated crimes within three years after the release. That means that correctional facilities only temporarily isolate the convicted person from the society, but their correctional function is insignificant; certainly they do not return their former inmates into normal life. The consequence is that the crime rate is on the rise in the country.

### O Advocating for the rights of sex workers

The valid laws have a negative effect over the people providing sex services in return for remuneration. The stigmatizing provisions of the laws have an effect over the quality of life and health of both women and transgender sex workers. The law enforcement bodies use the valid laws and policies to report on the planned number of disclosed crimes and use sex workers for these purposes. There is the evidence that by unlawful

deeds, extortion, fabricating material evidence or obtaining it by unlawful methods, using the law on combatting human trafficking, the police imputes sex workers the breaches of the Code of Ukraine on Administrative Offenses (Torts) accusing them of prostitution, fabricates criminal cases for pimping. While collecting evidence to accuse a defendant in prostitution, the police violates the procedural standards and the Law of Ukraine "On Police". Often accusations are imposed without any evidence — it is enough for them to find condoms in a purse or to find a person at so-called "cruising sites" where sex workers usually work. This treatment practiced by the police results in a quite considerable "closedness" of this most-at-risk group to social programs, including HIV/AIDS prevention ones. The prevention programs themselves become less effective, suffering from the lack of access to the target group. Serious challenges are observed in the course of HIV counseling and testing as well as distribution of condoms. Sex workers themselves choose to have as few condoms with them as possible. As a consequence, they are likely to have no means of protect their health from infections and undesirable pregnancies during a sexual intercourse.

Sex workers are reluctant to seek healthcare services or legal aid with the purpose to prevent or react to the violence committed by clients, police, partners or other perpetrators. It is quite challenging to start the process of building tolerant attitude to most-at-risk groups in general, and to sex workers, in particular, because the society's perception of sex work is quite conservative to sex work due to religious and pseudomoralistic biases. Most of the people think that sex workers well deserved contracting HIV and the stigma grows. Sex workers do not disclose their status while consulting doctors, therefore a practitioner is not in the position to prescribe treatment correctly or provide respective recommendations to protect their health.

The biases and myths about sex work play their considerable negative role. There is a myth that sex workers' income is soaring and that they should be charged with higher fees for social and healthcare services. Police officers regularly extort money from sex workers and threaten to disclose their status as "a prostitute" to their friends and family members. There are containing mechanisms by other government bodies just as if this violence and misconduct is indulged; as a result, the corruption among police officers shows steady growth.

Sex workers often perceive the violence affecting them as a regular routine, as specific features of their job, as some usual thing; that is the reason they do not file complaints to the law enforcement regarding the deeds of perpetrators despite the misdeeds they commit, despite violations of their fundamental rights and freedoms.



#### Recommendations<sup>12</sup>

- 1. To ensure protection of the rights of PLWH and most-at-risk groups.
- 2. To set up mechanisms to ensure the rights of prison inmates and former prison inmates living with HIV/AIDS, drug dependence and TB to be granted with social and medical care.
- 3. To cancel the provisions on administrative liability of sex workers: to remove Article 181 (1) from the Code of Ukraine on Administrative Offences.
- 4. To allocate full funding for the National HIV/AIDS Program for 2013 to the tune of 932 million UAH (399 million for treatment).
- <sup>12</sup> Based on the National HIV/AIDS Advocacy Plan for 2012 www.hiv.org.ua/

- 5. To improve transparency and accountability of the state-run tenders and procurement processes.
- 6. To ensure procurement and uninterrupted supply of medicines for the people living with HIV.
- 7. Civil society organizations should advocate for procurement of quality drugs prequalified by WHO as a mandatory eligibility criterion for the state-funded procurements in 2013.
- 8. To recommend provision by the Cabinet of Ministers of Ukraine (the Commission of the Cabinet of Ministers on humanitarian aid issues) of "humanitarian aid" status for the medicines and medicinal products imported to Ukraine with the financial support of the Global Fund.
- 9. To ensure 100% funding allocated by the local budgets to procure HIV testing systems, treatment of opportunistic infections, maintenance of healthcare services system for PLWH.
- 10. To improve coordination with the international donors and civil society organizations both at the national and local levels.
- 11. To ensure opportunities for delivery of social services by NGOs with the funding secured by the government: to develop a procedure on designing and implementing the standards of social services.
- 12. To involve resources of small towns to address the problems related to HIV/AIDS and TB at the local level.

### Chapter 5

# THE RIGHTS OF OPIOID SUBSTITUTION TREATMENT PROGRAMS' CLIENTS

njection drug use is the key driver of the AIDS epidemic in post-Soviet Union countries. Around 90% of newly tested HIV cases occur in Russia and Ukraine. However, the access to HIV prevention, treatment, care and support services for injecting drug users remains very low in the mentioned countries. In Ukraine opioid substitution therapy (hereinafter — OST) is accessible pursuant to the law; however, the demand in it is satisfied only by 10%. The OST programs' clients are regularly pressured by the law enforcement. The programs are inaccessible geographically. Many clients have to cover long distances and spend many hours to get OST medicines. That constitutes a barrier for their job-seeking and normal family life. They are not able to travel around the country. In Ukraine also discrimination laws and practices are broadly applied affecting the people using drugs. As it was mentioned above the access to OST program is limited<sup>1</sup>.

In 2012, according to human rights NGOs, the situation with access to opioid substitution programs worsened. On March 27, 2012 the Order No. 200 of the Ministry of Health "On adopting the Procedure of implementing opioid substitution therapy program for patients with opioid dependence" was adopted. This Order with no obvious reason erects barriers for administration of OST drugs and leads to abandonment of the program whatsoever.

The government bodies of Ukraine, decision-makers think that the spread of drug abuse and the decay of the healthcare system present a threat to the national interests and national security (Article 7, the Law of Ukraine "On fundamentals of the national security of Ukraine"). But at the same time the government perceives drug dependent individuals not as patients in need of special medical treatment and social support, but as criminals. Respectively, the state policy aims to create a system of strict control over the people with drug dependence and by means of punishing them with imprisonment. The attitude of government is expressed through such its representatives as healthcare professionals at state-run and municipal healthcare facilities. While seeking to get medical care, individuals with dependence on drugs frequently face discrimination, denials, derogatory and degrading treatment.

Ukraine subscribed to a set of commitments at the international level to change the situation. One of these commitments was to implement opioid substitution therapy programs in the country. The National Program on ensuring prevention, treatment, care and support for HIV positive and people living with AIDS for 2009–2013 was adopted as the Law of Ukraine on February 19, 2009. The Program includes a chapter "Expanding the scope of opioid substitution therapy method's use" (Chapter III, item 2, Action Plan). The program entails enhancing the access of injecting drug users to OST and rehabilita-

<sup>&</sup>lt;sup>1</sup> The chapter has been drafted by Andriy Rokhansky, Ihor Skalko.

tion programs. Not less than 20,000 injecting drug users are expected to benefit from access to opioid substitution therapy and rehabilitation programs. The government bodies report to the international organizations on access to OST for injecting drug users who were not able independently to drop the use (the Sixth periodic report of Ukraine on implementation of the International Covenant on economic, social and cultural rights).

But the real picture is not that optimistic. According to experts' estimates, not more than 10% of the demand is satisfied with access to OST; OST programs' clients, OST sites staff, healthcare professionals are pressured by the police. In many cases the programs are geographically inaccessible or the clients have to spend a lot of time to get the medicines. These problems contribute to their failure to find a permanent job and interfere with their family life. Also their right to freely travel around the country is breached.

**Solutions for the problem:** the meaningful dialogue of the Government of Ukraine and civil society in the context of international human rights commitments, particularly, the right to health is of vital importance.

This dialogue should be focused on the theme that OST availability and accessibility and needle exchange programs constitute the issues of compliance with the international commitments, namely the right to the highest attainable standard of health, especially in the countries where injecting drugs is the core HIV transmission route.

This dialogue is possible if it is mediated by a recognized and qualified expert on the right to health. Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health may be such an expert.

According to experts, advocacy capacity of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, UN Human Rights Council, (hereinafter — the Special Rapporteur) is not used, although it is very promising. The point is that the use of other international advocacy tools to have an impact over the Government is very challenging. Complaining to the European Court of Human Rights takes a lot of time, it requires exhaustion of the national instruments to restore the breached rights. The experience of the Institute for Strategic Researches and Strategies shows that injecting drug users do not file lawsuits to protect their right to health; respectively the procedure of complaining to the European Court of Human Rights is almost impossible for them. The procedure of complaining to the Special Rapporteur is almost simple, guarantees confidentiality of an applicant; the timeframe for response to be provided for an application is not that long.

The Institute for Legal Researches and Strategies lawyers held preliminary consultations with representatives of the NGOs providing services for injecting drug users (IDUs), particularly, Maksym Demchenko, Light of Hope NGO, Poltava, Serhiy Klyucharyov, Parus foundation, Kharkiv, Oha Bilyayeva (ASTAU). They expressed their interest in the tool of complaints to be submitted for consideration of the Special Rapporteur and confirmed that the problem of access to OST programs for IDUs is high on the national agenda.

These NGO also helped with meeting with the clients who do not have an access to OST. E. g. the video address of a woman was recorded in Poltava: she could not manage to be included into the OST program for a year. Within this year she contracted HCV as a result of injecting drug use.

The Special Rapporteur (incumbent Anand Grover) is an independent expert appointed by the UN Human Rights Council to study and report on the situation in a specific country or on a specific human rights topic<sup>2</sup>.

<sup>&</sup>lt;sup>2</sup> More details on the mandate at http://www2.ohchr.org/english/issues/index.htm

The Special Rapporteur expressed concern about the development of OST programs in Ukraine. Thus, on February 14, 2011 he sent a letter to the Government of Ukraine re interference of the law enforcement with the work of the opioid substitution therapy program in Ukraine.

The letter included a statement that delivery of opioid substitution therapy for drug dependent patients in Ukraine was severely impaired by the interference and checks of the patients' confidential data. These interventions were initiated by the General Prosecutor's Office staff, MoH officials and other supervising bodies of Ukraine.

On July 1–2, 2011 the Special Rapporteur had a meeting with the representatives of the Institute for Legal Researches and Strategies in Moscow. The Special Rapporteur expressed his interest in cooperation with civil society organizations in Ukraine concerning better access to OST programs.

The parties at the meeting also shared the same opinion that the situation with OST programs' implementation could be improved if the fruitful cooperation and the dialogue between the Government of Ukraine and civil society will be instituted. Currently this dialogue rotates in vicious circle of a discussion around the issues of OST efficiency — which looks like an unnecessary invention — there is the global evidence that OST is efficient.

This strategy is in full compliance with provisions of Article 11 (a) of the Code of Conduct for mandate holders), «Visit to a country».

The "stakeholders" notion is explained in the Preamble to the Code of Conduct. It goes:

"Considering that it is necessary to assist all stakeholders, including States, national human rights institutions, non-governmental organizations and individuals..."

In the course of the field visit the first dialogue should be conducted. It will focus on developing a "roadmap" to overcome the key problems on the way to promote the right to health for injecting drug users in terms of their access to OST.

Currently Ukraine received clear recommendations from the Committee on Economic, Social and Cultural Rights (CONSIDERATION OF REPORTS SUBMITTED BY STATES PARTIES UNDER ARTICLES 16 AND 17 OF THE COVENANT, Concluding observations of the Committee on Economic, Social and Cultural Rights, UKRAINE, 28, 51). The considerations include a recommendation to ensure broad application of OST and harm reduction programs, including at penitentiary settings.

These recommendations as well as the complaints to the Special Rapporteur should serve as baseline points for the dialogue of the Government of Ukraine and civil society with the mediation of Anand Grover, the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.



#### — that's how the OST clients call this Order...

On March 27, 2012 the Order No. 200 of the Ministry of Health of Ukraine was adopted: "On adoption of the Procedure to implement opioid substitution therapy for the patients with opioid dependence", which gave rise an outburst of negative feedback — both by OST clients and human rights activists.

Let us consider in more detail why this Order aroused so much anger<sup>4</sup>.

 Article 5 the Procedure to implement opioid substitution therapy for the patients with opioid dependence adopted by the Order of the Ministry of Health No. 200 as of March 27, 2012. OST

<sup>&</sup>lt;sup>3</sup> "Cargo 200 is a military term defining transportation of the persons who were killed or died in a special sealed container (sealed zinc coffin) to the place of burial. The term was coined and became popular after the Soviet war in Afghanistan. More generalized use: a "200th" is the killed soldier.

<sup>&</sup>lt;sup>4</sup>The coments were drafted by Ihor Skalko, OST Coordinator (at Mykolayiv Central District Hospital).

programs eligibility criteria include: 18+ age of a patient; a written request of an applicant to start OST; documented evidence for at least two previous unsuccessful attempts of drug dependence treatment.

The comments: the eligibility criterion on "documented evidence for at least two previous unsuccessful attempts of drug dependence treatment" is in breach of the principle of anonymous treatment set forth by Article 14 of the Law of Ukraine "On measures to control the illegal trafficking of narcotic drugs, psychotropic substances and precursors and their abuse".

Additionally, this criterion is totally incompliant with one of the key fundamentals of Ukrainian health law: pursuant to it is the patient who has the right to choose a method of treatment (Article 6, 38, the Fundamental of the Laws of Ukraine on health care).

Besides, making the program a high-threshold one (providing documented evidence, which is highly improbable for applicants) will result in escalation of corruption in healthcare (these documents will be fabricated in exchange for bribes) and will remove the very opportunity for most injecting drug users to get access to OST. This last development will contribute to more cases of contracting HIV via needles.

 Article 8 "The Commission is entitled to take a decision on minimum and maximum dose of the Drug and the timeframe for its use by means of filling in the primary accounting form No. 129-3/o "The Conclusion on prescribing opioid substitution therapy medications".

**Comments:** we suggest abolishing the very institution of commissions as being absolutely absurd. In reality all these commissions are just bureaucratic formalities. These commissions' members are the professionals who have nothing in common with OST.

It is the practitioner only who should be authorized to responsibly prescribe the drug and urgently amend its dosage if there is a need.

We consider these commissions to be an obsolete mechanism; if it is abolished, it will just save tons of paper and thousands of trees.

Besides, the draft of the Cabinet of Ministers' Decree on handling narcotic drugs at healthcare facilities does not include this institution.

"1. Form No. 129-3/o "The Conclusion on prescribing opioid substitution therapy medicines" (hereinafter — Form No. 129-3/o) shall be filled in by the Commission on expedience of prescribing narcotic drugs at the healthcare facility thereof (hereinafter — the Commission) on opioid substitution therapy; the Commission is supposed to include a Chair of the Commission and two narcologists (drug treatment doctors)"<sup>5</sup>.

**Comments:** Thus, currently there are a lot of healthcare facilities implementing OST programs are not authorized to prescribe narcotic drugs, because they do not have 2 narcologists in their staff list.

 Article 10. In case there is a need to get OST services at a healthcare facility located in the other region (change of the place of residence, business trip, vacation, etc.), an OST patient is entitled to approach a healthcare facility in that region with a request to get OST services there.

To attain the permission a patient shall submit a request to ensure OST provision for him/her at this healthcare facility; the copies of the passport pages (the first one, the second one and the page with the data on the most recent residence registration) as well as the verified excerpt from the patient's medical personal file maintained at the facility where the patient was provided with OST services in compliance with the laws of Ukraine.

The patient shall produce his/her passport in person while filing the application.

<sup>&</sup>lt;sup>5</sup>The instruction on filling in the primary accounting form Form No. 129-3/o "The Conclusion on prescribing opioid substitution therapy medicines" adopted by the MoH Order No. 200 as of 03/27/2012.

...

The medical file excerpt shall be filed with the attached copy of the document (properly certified copy (excerpt) of the order on a business trip or vacation) that confirms the need in getting OST services at a healthcare facility located in the other region and serves as a justification for issuing the excerpt thereof.

The Commission shall consider and decide on an application with a request to continue OST at this healthcare facility within three days since the application has been filed. Upon taking the decision it shall inform the patient and the practitioner at the healthcare facility where the patient with opioid dependence is provided with OST.

**Comments:** first of all, this article limits the right of a patient to freely choose a healthcare facility; secondly, it limits the right for free movement secured the Law of Ukraine "On freedom of movement and free choice for residence in Ukraine", because movement is dependent on the availability of an order on a business trip or vacation.

Besides, dependence on availability or a lack of passport, which may be missing at the moment of movement, also limits the right of a patient and of a human being. This provision on the passport should be substituted with the wording: "...any authorizing document (a passport of a citizen of Ukraine, a passport of a citizen of Ukraine for visits abroad, diplomatic passport, business passport, a sailor's ID document, professional ID document, driving license or other document issued by a government body, comprising such mandatory entries as the last name, name, parental name, a photo, the signature of the official in charge, a stamp of the institution that issued the document and the date of issuance.

Most patients are unemployed; many of them do not have an official residence registration mark in their passports. The requirement breaches the provisions of the Law of Ukraine "On freedom of movement" and is very like the situation in Soviet times when passports were not issued for rural regions' residents to prevent their escape from villages.

Besides, if the provision stating "the Commission shall consider and decide on an application with a request to continue OST at this healthcare facility within three days since the application has been filed. Upon taking the decision it shall inform the patient and the practitioner at the healthcare facility where the patient with opioid dependence is provided with OST" is enacted, some "migrating" patients will suffer from withdrawal syndrome and may relapse into illicit drug use, nullifying the effect of the previous treatment. Or one will have to approach the facility with a request "to speed up the decision", which may result in corruption.

Article 12. In case of admission of an OST patient into an in-patient facility, a chief of a healthcare facility, seeking to ensure the treatment continuity, shall send a written request to the Minister of Healthcare of Autonomous Republic of Crimea/the chiefs of healthcare departments of regional state administrations, Kyiv and Sevastopol city administrations to ensure the transfer of the Drug from one facility to another with strict compliance with the procedure of handling narcotic drugs, psychotropic substances and precursors.

**Comments:** it is an extremely obsolete provision; the procedure for transfer of the drugs was already implemented in many regions by means of issuing respective orders. One should provide the healthcare facilities possessing licenses for narcotic drugs with more freedom. The prescribed agreements may take a lot of time, and the patient in question will be discharged by the moment the decision is taken.

Article 13. OST shall be provided by a practitioner with a qualification of narcologist or who has been re-trained at the specialized training courses on OST pursuant to the methodology adopted by the MoH orders.

**Comments:** What about other doctors at other healthcare in-patient facilities where OST patients are admitted? This provision could be

very instrumental for the controlling law enforcement bodies, e. g. VBNON (Drug Control Police Unit).

- Article 17. The decision on suspending OST shall be taken at the meeting of the Commission upon the submission of a practitioner in the following cases:
  - A patient's submitted request on refusal from further participation in OST program;
  - Infringement of the OST admission procedures established by the orders of the MOH by a patient;
  - Attempts to take the drug out of healthcare facilities;
  - Interruptions in taking the drug for more than 10 days within a month;
  - A court's ruling or administrative proceeding's outcome comes into force;
  - Urine test shows the presence of narcotic drugs in the body of a patient.

**Comments:** First, "A court's ruling or administrative proceeding's outcome comes into force": what should do with a person on parole or fined or for the breach of road regulations?

But the most dangerous provision is about *Urine test shows the presence of narcotic drugs in the body of a patient* — this provision just crisscrosses the very foundations of the program, harm reduction principles. The very disease is characterized by potential failures and "relapses" into use of regular illicit drugs, especially at the initial stage. One should bear in mind the potential soil for corruption here...

**General conclusion:** the Order No. 200 of 03/27/2012 of the Ministry of Health of Ukraine "On adoption of the Procedure to implement opioid substitution therapy for the patients with opioid dependence" may be assessed as an extremely poor. It was drafted either upon the order of OST opponents or by the people having none of the slightest idea how to conduct a practical work with drug users.

**General conclusion:** the Order No. 200 of 03/27/2012 of the Ministry of Health of Ukraine "On adoption of the Procedure to implement opioid substitution therapy for the patients with opioid dependence" may be assessed as an extremely poor. It was drafted either upon the order of OST opponents or by the people having none of the slightest idea how to conduct a practical work with drug users.

# 2 OST program regional success. In Poltava region local budget funding was allocated for opioid substitution program

10/03/2012

"In fact that is pioneering step in Ukraine when a substantial change occurred in regional drug policy", — Serhiy Zhuk, Light of Hope Senior Advocacy Officer reports.

The most important thing is that the changes to ensure human rights and humanistic attitude to drug users are substantiated by the real practical steps. Thus, despite everlasting budget deficits, the Regional Council allocated more than 10 million UAH to finance the Regional Drug Addiction Control Program. The program's activities have been drafted in compliance with the best international standards; they are grouped in accordance with three major areas: Demand reduction, Supply reduction and Harm reduction. Funding was allocated for each of the strategy areas: e. g. harm reduction efforts will be funded to the tune of 4.2 million UAH by the regional budget. The interventions will include needle exchange points, outreach routes, community centers for injecting drug users in Poltava, Kremenchuk and Lubny and OST program for drug users.

That was the first step to switch funding for the programs from the Global Fund to the regional and city budgets.

The expansion of the OST program by 5 patients (since September this year) as a result

of procurement of domestically produced Buprenorphine by the funds of the regional budget constituted an important step forward and the conformation that the program will continue its operations. This meaningful event will provide for allocating funds to procure the drug to provide 50 patients with treatment; that will constitute almost 10% of the total number of OST patients.

The case study testifies to the fact that despite all barriers, civil society can and should advocate for changes, particularly in the sphere of HIV and drug policy. Remembering that the local government systems in other regions are quite similar to Poltava one, we hope that the Light of Hope success story will inspire all those who do not believe in positive changes.

## Criminalization of drug users should be urgently reduced<sup>6</sup>

The current system of combating the illicit drug trafficking and respective punishments are based on the Tables of small, large and especially large amounts of narcotic drugs, psychotropic substances and precursors used in illicit trafficking (hereinafter — "The tables of drugs amounts"). It is this policy adopted by the Order of the Ministry of Health on August 1, 2000 that the inquiry agencies, pre-trial investigation police bodies and the courts use while assessing a possession of a certain amount of illicit drugs whether as an administrative tort (Article 44, the Code of Administrative Offences) or as a criminal offence (Article 309 of the Criminal Code of Ukraine) and establish qualifying features for other drug-related crimes.

Since October 29, 2010 after adoption of the Order of the MoH as of July 29, 2010 and after the new version of the Tables of drug amounts came into force, the criminalization of injecting drug users who used opiates (opium and acetylated

 $^6$  The National HIV/AIDS Advocacy Plan 2012 — www.hiv. org.ua

opium) — the most frequently used category of drugs — increased by 5–20 times.

The current cases considered in court's room provide prove that even the leftovers of acety-lated opium in the used syringe may constitute a sufficient material evidence to press a charge against an individual as prescribed by Article 309 of the Criminal Code of Ukraine. Bearing this fact in mind, injecting drug users have justified fears to have used syringes with them and to bring them to needle exchange points.

This problem is directly related to at least 59,800 individuals or 76% of all officially registered (within MoH dispensary registry) persons with chronic dependence on opioids. Thus, certain provisions of this Order erect a barrier for implementation of the government guarantee specified in Article 4, part 8 of the Law of Ukraine "On counter measures to control the spread of the diseases related to human immunodeficiency virus (HIV) and legal and social protection for the people living with HIV". Its last edition as of December 23, 2010 guarantees HIV prevention focusing injecting drug users with utilization of harm reduction programs, which, inter alia, provide for exchange of used injecting needles and syringes with sterile ones and further disposal of the used ones.

### 4 OST implementation problematic issues

- Some healthcare facilities have not launched OST so far; centralization of treatment is a barrier to achieve universal access to OST;
- There are problems with ensuring continuity of OST in cases of admitting patients to the respective healthcare facilities: the MoH Order was issued, but it is not implemented in more than 50% of regions. There are problems with treatment of opportunistic infections. There are even AIDS centers, which as of now (11/01/12) have not launched OST pursuant to the MOH Order;

- The problems with violations of the OST patients' rights by the police and healthcare professionals; the consequence is that drug users are apprehensive to start OST or quit the treatment; OST may provide treatment for 1285 additional patients;
- There is no access to OST for the patients detained for committing infractions, kept in custody and the convicted.

## (5)

#### Recommendations

- 1. To expand the access to opioid substitution therapy programs and improve the quality of services.
- 2. To introduce liquid formulations of methadone into OST implementation.
- 3. To develop mechanisms to ensure OST continuity for the patients kept in pre-trial detention centers, police detention centers and places of imprisonment at the national and regional levels.

- 4. To promote implementation of the Order No. 1054 of December 12, 2009 (Article 2.5) on ensuring OST continuity for the patients admitted to in-patient departments of healthcare facilities (general or specialized ones). To expand the prescription-based regimen of OST medicines.
- 5. To cancel the Order No. 200 of MoH of Ukraine as of March 27, 2012 "On adoption of the Procedure of implementing opioid substitution therapy of the patients with opioid dependence".
- 6. To issue a new MoH Order "On adoption of the Procedure of implementing opioid substitution therapy of the patients with opioid dependence" taking into account the recommendations by independent experts.
- 7. To bring the standards of the MoH Order No. 634 of 07/29/2010 regarding small, large and especially large amounts of illicit drugs in compliance with the daily doses for statistical purposes (S-DDD) determined by the INCB.
- 8. To conduct permanent monitoring of police misconduct regarding drug users and, in particular, police interference with harm reduction programs' work.

### Chapter 6

# THE LAW OF UKRAINE "ON PSYCHIATRIC CARE" IN THE CONTEXT OF HUMAN RIGHTS

he Law of Ukraine "On Psychiatric Care" was adopted on February 22, 2000 and has brought a lot of troubles and sorrows to mental health patients and their family members. One may state that it destroyed the psychiatric care system as it had been in Russian Empire and in USSR. Many consider this development to be positive one: under Soviet times repressive psychiatry existed; many dissidents became its victims. However, at Soviet times in addition to repressive one, there had been a regular psychiatric care — efficient and effective<sup>1</sup>.

Mental health patients were provided with appropriate, fast and quality care. Although the living conditions at in-patient mental health facilities were quite modest, they did not starve and were provided with necessary medicines free of charge.

Now all these achievements are missing. Nutrition regime is very inferior at mental health facilities and free medicines are prescribed in compliance with the principle of their low price, not their efficiency. But it was not the lack of funds that struck the heaviest blow over psychiatry, but the law itself. Article 11 of the Law includes a provision on the informed consent of the patient for an examination to be conducted by a practitioner: "Psychiatric examination shall be conducted by a psychiatrist upon the

request or upon the informed consent of an individual thereof". In other words, if a person is considered legally capacitated, neither family members, nor third parties are authorized to have the patient examined by a psychiatrist. But it is universally known that one of the symptoms of endogenous sickness — schizophrenia, manic depressive disorder — is a lack of critical attitude towards one's own condition. Hence, a schizophrenic will never consent to an examination by a psychiatrist, because he/she considers his/her in sound mind. He/she associates the attempts to treat him with some enemy powers. But what should the patient's family members do if they witness the features of a disease? Call a psychiatrist? Well, it is possible. But, in accordance with the law, while visiting a patient a psychiatrist shall produce the credentials, tell the patient that he/she is a psychiatrist and ask the patient whether the patient wants the doctor to examine him/her. Surely, most patients decline this offer and the psychiatrist leaves. But the disease remains with the patient, and sometimes, quite often, he/she may pose a threat both for the patient's own safety and for those who are nearby.

The belated treatment may lead to a suicide or have severe consequences for the patients' family. There are a lot of examples, because KhHPG provides support for the patients' family members. Here is one of these examples:

<sup>&</sup>lt;sup>1</sup> The chapter has been drafted by Inna Sukhorukova, Serhiy Kholtobin.

A woman approached KhHPG with a complaint: her daughter, a mentally health patient, subjects her grandson and her to beating.

The woman called the mental health ambulance team, but the daughter refused from examination. She also called the police; the police is authorized to call the ambulance as well, although they are very reluctant to do that. In this very case the police officers upon their arrival declared that these were their own domestic affairs. "The domestic affairs" ended in the severe beating inflicted to her child; the child was admitted to the hospital, diagnosed with concussion. KhHPG submitted requests to the board of trustees and the Prosecutor's Office. The Board of Trustees deprived the mother of her parental rights; the grandmother was assigned to be the minor child's guardian. But nobody proceeded with treating the patient. The police and the prosecutor's office never contacted with healthcare professionals. And the patient herself did not express any wish to be treated.

Here is one more case, which is still pending.

Patient B. has experienced mental disorders since his childhood, was frequently treated at a mental health healthcare facility for underage persons, was registered at the mental health dispensary but he was never diagnosed with "schizophrenia". He was diagnosed with "psychopathy"; this diagnosis made him ineligible for army service. When he was 28, all of a sudden he started to consider himself to be a girl, to wear women clothes and take women hormones estrogens. The parents did not understand at once that it was a symptom of a mental disorder; but when they found out he managed to make a lot of debts by borrowing loans; he bought 3 cars and did a lot of strange things. They understood that it was symptom of the disease he had had in his childhood. Considering B. to be posing threat for his own safety, the parents called the ambulance. The ambulance brought B. to the mental health clinic, but he refused from the examination by psychiatrists, respectively he was allowed to leave

The parents filed a request to the court, but the court chose to decline their motion before consideration and did not assign a mental health examination. Currently the parents are not aware where their son is — he severed contacts with them. The only thing they know that the bank where he got loans and did not return them filed a lawsuit to the court to impose arrest on his property. In this case the court acted rapidly and issued a permission to impose an arrest over the B.'s property. The patient's parents file a new complaint to the court supplying new documents and requesting to assign a new mental health examination for B. But it is not clear what the final result will be.

According to psychiatrists, both courts and the police are very reluctant to issue permissions on forced (involuntary) treatment, leaving the patients without any medical care.

Neighbors helped a lot in one of the cases where an aggressive mental patient was involved. Patient N. was diagnosed with "schizophrenia" but preserved his legal capacity. He was not treated, his disease developed. N. became aggressive; he beat his children and his wife. The neighbors heard screams and sounds of beating almost every day. But the police, as their custom was, did not intervene, justifying their own inaction by the pretext that this was their "own home problems". When once neighbors tapped on the door of the flat during the fight, N. started to threaten them and they called the police. N. was delirious and the police called the mental health ambulance. N. was hospitalized and currently treated. KhHPG advised the neigbors to do so. Fortunately, the neighbors were smart and showed no indifference.

This law challenges the normal work of psychiatrists. They identify people with mental health disorders and pose a threat for those who are near, but they do not have any legal tools to treat such a person. Only due to the fact that the employees funded from the government budget are afraid lest they lose their jobs, that there are no public protests by psychiatrists concerned with this law and the related situation. KhHPG submitted a request to Ms. Bohatyryova, the

Minister of Health to review this law, but there have been no response so far.

Patients, not only their family members, approach us with requests. They complain about some problems, in most cases imaginary ones. But we may see that there is a need to treat them. However, all our requests to psychiatric dispensaries remain vain, because the patients do not provide "informed" consent to examination by doctors and treatment — they are not aware that there is a need in care.

As for repressive psychiatry — the law does not save from it. There is a repressive psychiatry in the independent Ukraine as well. We came across the situation like this in the case with R.

This patient was diagnosed with "schizophrenia" long ago. But he was treated rarely and did not attend the dispensary. Obviously, the relevant medicines were not administered. So, when this case occurred, he was not under medical supervision. Hence, it is not possible to concise to what extent he was ill.

According to the official version of the investigating officers and the court, R. beat the girl so hard that she was admitted to a hospital where she underwent surgery. According to the version by R's mother, the police unlawfully restricted his liberty, because he had been beaten by the police so severely that he was hospitalized to neurosurgery department diagnosed with concussion; he could not beat the girl, because he was in the other place. Let us not get into so much detail, as we are mostly interested in medical aspect of this story. The investigating officers had R. examined by a psychiatrist; the examination showed he had a mental disorder. Pursuant to the medical examination's report the court ruled out to hospitalize R. to a Ukrainian mental health hospital with severe supervision located in Dnipropetrovsk; he was recognized to be socially dangerous.

This event would not have occurred if the Law of Ukraine "On Psychiatric Care" had not entrusted his fate into his own hands and the patient had been treated in time (if the police version on his fault in beating the girl was correct).

But when the patient stayed at the mental hospital with strict supervision, they started to treat him with strong neuroleptics he could not stand: Kharkiv Regional Mental Health Hospital No. 3 confirmed this fact in a written form. When the mother attended the son at the hospital, he was emaciated and had convulsions. KhHPG lawyers sent a request to the chief doctor to get information about the medicines applied in the course of treatment for R., but there was no response. So they had to file a lawsuit against the management of the hospital. The court obligated the chief doctor to respond to KhHPG lawyers. It is only after this intervention that the other medicines were chosen to treat R. So, as we see, the disease, which was not treated or treated insufficiently, may produce tragic results. But the Law does not prevent from repressive psychiatry.

Currently the lawsuits by R. against the police and the investigating officer are pending in courts. KhHPG lawyers represent the interests of R. in court.

Family members of A. approached us with a request to help with hospitalization of the patient. A. himself approached KhHPG with a complaint that he was being persecuted by the Security Service of Ukraine and that he was in danger of an attempted murder. A.'s former wife wrote to us that A. had a severe mental disorder. In 2007 he was treated at Kharkiv Regional Mental Health Hospital No. 3. Now his condition deteriorated. The ex-wife met with the chief of the department of the in-patient facility where her former husband had been institutionalized. The practitioner noted that the patient must be urgently admitted to a hospital. But A. is absolutely against it, because he considers his state of mind to be sound. He persecutes his ex-wife and the daughter and convinces them that the KGB wants to kill them. In the result the daughter had to leave Kharkiv. Being in this mental state, he attempted to get into the house of his wife's elderly parents and tampered with the door, trying to break into the house.

The wife called the police, told about the disease A. had and asked to institutionalize him. But

the police only talked with him, asking him not to misbehave. The police left and the problem remained.

Currently A. proceeds with persecuting the wife and her parents. KhHPG's requests submitted to the dispensary produced no results. We were explained that A. might be hospitalized only by means of simultaneous call for the ambulance and the police if the police express a wish (!) to take part. Currently the problem has not been solved.

The Law of Ukraine "On Psychiatric Care" includes one more unacceptable provision. Article 11, part 2 of the Law states: **Psychiatric** care examination shall be conducted by a psychiatrist upon the request or upon an informed consent of a person; a minor (aged less than 14) shall be examined upon the request or upon the consent by his/her parents or other legal representative; a legally incapacitated person shall be examined upon the request or consent of the person's guardian. In case of denial of one of the parents or lack of parents or other legal representative, psychiatric care examination shall be conducted pursuant to the decision (consent) of the bodies of trustees and guardianship that may be appealed to the court (Article 11, part 2 with amendments introduced in compliance with the Law of Ukraine as of May 17, 2007), i. e. a mentally handicapped child may be examined only upon the informed consent of both parents. But one of the parents may have no understanding that a child needs an examination by a psychiatrist. A parent may be just scared of contacts with psychiatrists.

Several years ago a young divorced woman approached KhHPG with a complaint. Their 5-year-old son was obviously mentally retarded, but her ex-husband did not provide a permission for an examination by a psychiatrist, despite the fact he had seen very little of the child. Hence, the

boy was growing up without proper observation by doctors; respectively, his condition was deteriorating. Then the efforts by KhHPG helped to ensure examination for the child.

But the Law's negative impact is still in place. There are so many children like this one without proper medical care.



#### Recommendations

1. To create a task force, including best experts, scientists and mental health practitioners; the task force's objective will be to draft a new version of the Law of Ukraine "On psychiatric care".

- 2. The special focus should be made on:
- a) Article 11 of the Law of Ukraine "On psychiatric care": "Psychiatric examination shall be conducted by a psychiatrist upon the request or upon the informed consent of an individual thereof"
- Article 11, part 2 of the Law: "Psychiatric care examination shall be conducted by a psychiatrist upon the request or upon an informed consent of a person; a minor (aged less than 14) shall be examined upon the request or upon the consent by his/her parents or other legal representative; a legally incapacitated person shall be examined upon the request or consent of the person's guardian. In case of denial of one of the parents or lack of parents or other legal representative psychiatric care examination shall be conducted pursuant to the decision (consent) of the bodies of trustees and guardianship that may be appealed to the court".

### Chapter 7

### LGBT COMMUNITY HEALTH RELATED RIGHTS

uman rights activists' efforts are necessary for the society in general. The state machinery would easily cut our rights and freedoms if these efforts are not undertaken. Human rights activists' work constitutes a counter balance preventing such a development" Svyatoslav Sheremet, Gay Forum of Ukraine, all-Ukrainian LGBT association leader says. — The concept of human rights is universal. That means that one cannot advocate for freedom of confession, but at the same time ignore the abuses related the sexual orientation. It is great that human rights activists started to actively "pursue" the problems Ukrainian homosexuals experience<sup>1</sup>. It is great that human rights advocates are brave enough to speak about homophobic initiatives of our law makers. I am sure the Parliament, the President, the Government and the Ministries will implement the recommendations by human rights activists".

## 1 Problem's urgency

The key underlying reasons for the epidemic affecting MSM include a risk sexual behavior and a high degree of social discrimination<sup>2</sup>. The dis-

crimination is the reason why men do not consult healthcare facilities and civil society organizations to be provided with information on HIV/AIDS prevention and treatment, because that would result in disclosing their homosexual behavior. Hence, stigma and discrimination contribute to further vulnerability to the infection and disease. The national data do not reflect the scale of HIV epidemic related to sexual intercourses of the persons of the same sex. According to the official statistics, since the inception of the epidemic in Ukraine (1987) only 410 persons contracted HIV by homosexual intercourse route. According to the special survey's findings conducted in 2009, the prevalence rate among MSM was estimated at 8.6%. In some cities the prevalence was even higher: Odesa — 21.7%, in Donetsk — 19.9%, in Lviv — 19.3%, in Simpheropol — 9.2%, in Kyiv — 7.7%. One should note that the number of MSM in Ukraine was estimated at 95,000 — 213,000 aged 15-49 (according to 2009 survey). The estimations of the number of WSW and surveys on their role in HIV/STI epidemic have not been undertaken.

## Civil society and human rights organizations' efforts

As of February 20, 2012 18 non-government organizations conducted prevention activities targeting MSM with the financial support provided by the International HIV/AIDS Alliance in Ukraine

<sup>&</sup>lt;sup>1</sup> General info on the problem: Human rights in Healthcare — 2011. — Kharkiv: Human rights, 2012 — 208 p.

<sup>&</sup>lt;sup>2</sup> Sarankov Yu. A., Yaroshenko A. A. Some aspects of SM health problems. Methodology recommendations on HIV and MSM issues for healthcare practitioners: Methodology guide / United Nations Development Program in Ukraine. — Edited by Yaroshenko A. A. — Authors: Geydar L. M., Mostyayev O. I., Sarankov Yu. A., Yaroshenko A. A. — K., 2011. — 80 p.

in 16 out of 27 administrative territorial units<sup>3</sup>: 11 oblasts (Dnipropetrovsk, Donetsk, Zaporizhya, Kyiv, Lviv, Mykolayiv, Odesa, Rivne, Ternopil, Kharkiv, Kherson, Cherkasy, Chernivtsi), cities of Kyiv, Sevastopol and Autonomous Republic of Crimea.

## The projects targeting MSM includes delivery of the following key services:

- dissemination of condoms and lubricants on outreach routes;
- group and individual counseling sessions on safe sexual behavior, HIV-infection/ AIDS and STI;
- trainings focusing on safe behavior, including motivating to use condoms and lubricants;
- HIV-related voluntary counseling and rapid testing, STI testing and their treatment;
- disseminating information materials;
- holding meetings of self-help groups;
- individual and group counseling sessions by a psychologist;
- peer counseling;
- holding self-help groups, including those for MSM living with HIV;
- referrals to services provided by partner organizations and institutions;
- disseminating information on available services in the community.

## Besides, some projects entail additional activities targeting MSM, including:

- HCV and HBV rapid testing as well as hepatitis B vaccination;
- disseminating femidoms;
- Awareness raising and prevention leisure, including parties aimed at building safe sexual behavior;
- providing advice on-line (via social networks);

- disseminating information materials;
- mentoring program.

## 3 The most frequent health problems4

The study targeting Ukrainian MSM produced the findings that in 2009 they mostly had such STI as: *trichomoniasis* (1.7%), *gonorrhea* (1.6%), *chlamidiosis* (1.4%), *syphilis* (0.6%), *genital herpes* (0.5%)<sup>5</sup>. The analysis of the syphilis prevalence at the national level shows that it is lower than that of HIV; median prevalence (in accordance with the results of rapid tests) is identical for various age groups and constitutes 2.2%. The highest syphilis prevalence is observed among MSM in Donetsk (7.3%) and Kherson (7.6%)<sup>6</sup>.

This list may be added with the higher risk of being infected with diseases affecting the gastro-intestinal tract (amebiasis, shigellosis, cryptosporidiosis). These infectious diseases have oral and anal route of transmission as a result of unsafe sexual practices, specific for MSM.

Infecting human papilloma virus, 16<sup>th</sup> type associated with development of rectal cancer with men. According to some surveys, around 90% of HIV-positive MSM and 65% of HIV-negative MSM have human papilloma virus<sup>7</sup>. Anal squamosal intraepithelial damages of mucosal membrane of low and high degree are the factors that may

<sup>&</sup>lt;sup>3</sup> Geydar L. M. Ensuring human rights in the context of HIV/AIDS epidemic: Ukraine's best practices. Methodology recommendations on HIV and MSM issues for healthcare practitioners: Methodology guide / United Nations Development Program in Ukraine. — Edited by Yaroshenko A. A. — Authors: Geydar L. M., Mostyayev O. I., Sarankov Yu. A., Yaroshenko A. A. — K., 2011. — 80 p.

<sup>&</sup>lt;sup>4</sup> Sarankov Yu. A., Yaroshenko A. A. Some aspects of SM health problems. Methodology recommendations on HIV and MSM issues for healthcare practitioners: Methodology guide / United Nations Development Program in Ukraine. — Edited by Yaroshenko A. A. — Authors: Geydar L. M., Mostyayev O. I., Sarankov Yu. A., Yaroshenko A. A. — K., 2011. — 80 p.

 $<sup>^5</sup>$  Monitoring of the behavior and HIV prevalence among men having sex with men as a component of the second generation HIV epidemic surveillance: Analytical report on the findings of the linked 2009 / International HIV/AIDS Alliance in Ukraine". — K., 2011. — p. 62.

<sup>&</sup>lt;sup>6</sup> lb, p. 65.

<sup>&</sup>lt;sup>7</sup> Palefsky J. M., Holly E. A., Ralston M. I., et al. Prevalence and risk factors for human papillomavirus infection of the anal canal in human immunodefi ciency virus (HIV) — positive and HIV-negative homosexual men // Journal of Infectious Diseases. — 1998. — No. 177. — Pp. 362–377.

lead to development of anal carcinoma<sup>8</sup>. Cytological lab examinations of smear from the mucosal membrane of the rectum (PAP test) should be conducted with MSM once per two-three years; if the patient is living with HIV — these tests should be conducted more frequently.

## **(4)**

### **Barriers to HIV testing**

Non-acceptance of one's own sexual orientation (internalized homophobia or homonegativism) is the barrier to take an HIV test. It may lead to isolation with no opportunities to establish long-term relationships and practice or risky anonymous sex. MSM, who do not maintain contacts with gay community, usually are not provided with prevention info and means of protection, substantially increasing the risk of contracting HIV/STI<sup>9</sup>.

Being diagnosed with "HIV" is an enormous stress factor. Stigma index survey conducted by the All-Ukrainian PLWH Network provided for identifying the most typical for their psychological condition opinions, thoughts and negative feelings the LGBT HIV+ have regarding their HIV status.

Fears and concerns LGBT living
with HIV have regarding their HIV status<sup>10</sup>

My friends and family will avoid me	68
There will be gossips about me	65
Potential partners would not want to have sex with me	58
I will be offended or verbally abused	50

<sup>&</sup>lt;sup>8</sup> Chin-Hong P. V., Vittinghoff E., Cranston R. D., Browne L., Buchbinder S., Colfax G., Da Costa M., Darragh T., Benet D. J., Judson F., Koblin B., Mayer K. H., Palefsky J. M. Age-Related Prevalence of Anal Cancer Precursors In Homosexual Men: the EXPLORE study // Journal of the National Cancer Institute. — 2005. — No. 97 (12). — Pp. 896–905.

I will be physically persecuted	35				
People may think that I am chaotic in my relationships; That I am a MSM, SW or IDU					
I will not be able to get married	23				
I will lose my job or will be expelled from an educational institution					
I will be forced to leave home or move to the other place					
The police or other law enforcement bodies may attempt to launch criminal proceedings against me	8				

## 5

### **Council of LGBT organizations of Ukraine**

 is an all-Ukrainian association, uniting 21 LGBT NGOs of our country. The Council key focus is on comprehensive advocacy efforts to promote the rights, interests and needs of lesbians, gays, bisexuals and transgenders (LGBT).

On March 31, 2010 The Committee of the Ministers of the Council of Europe, represented by the national governments of 47 member countries unanimously adopted the historical "Recommendation CM/Rec(2010)5 of the Committee of Ministers to member states on measures to combat discrimination on grounds of sexual orientation or gender identity"11 (hereinafter — the Recommendation). This is the first global intergovernmental policy to ensure equal civil rights for gays, lesbians and transgender peoples. Ukraine became a signatory to the Recommendation without reservations and in full. The first assessment of the national governments' performance in terms implementation of the Recommendation will be conducted by the Council of Europe Committee of Ministers in 2013.

The Council of LGBT NGOs has been monitoring the implementation of the Recommendation; it maintains on-going cooperation with the Council of Europe and European Union's bodies, which shall observe Ukraine's compliance with its commitments regarding the CoE and EU —

<sup>&</sup>lt;sup>9</sup> Sarankov Yu. A., Yaroshenko A. A. Some aspects of SM health problems. Methodology recommendations on HIV and MSM issues for healthcare practitioners: Methodology guide / United Nations Development Program in Ukraine. — Edited by Yaroshenko A. A. — Authors: Geydar L. M., Mostyayev O. I., Sarankov Yu. A., Yaroshenko A. A. — K., 2011. — 80 p.

<sup>&</sup>lt;sup>10</sup> PLWH stigma index — Stigma Index: Survey report / All-Ukrainian PLWH Network. — K.: Engineeering, 2011. — 89 p.

<sup>&</sup>lt;sup>11</sup> The document's code is CM/Rec(2010)5.

through the mediation of the European Office of the International Lesbians and Gay Association (ILGA-Europe).

In 2012 Summary Report on implementation of the Recommendation CM/Rec(2010)5 of the Committee of Ministers of the Council of Europe on measures to combat discrimination on grounds of sexual orientation or gender identity by Ukraine was presented<sup>12</sup>.

### The summary of this report states:

The Ukrainian authorities have to all intents and purposes ignored the CMCE recommendation. From the time of its adoption up to this report's completion (September 2012) there have been no actions — whether enactments of laws or introduction of policies — aimed at implementation of the Recommendation, beyond publication of a few relatively minor documents. State bodies have not collected information related to discrimination on the grounds of sexual orientation or gender identity, and corresponding information from non-governmental organisations has not been examined and analysed. The interests and needs of LGBT persons as well as relevant proposals of LGBT organisations have not been taken into account in any way when developing legislative and the other measures. Even the simplest item of the Recommendation — its translation into the national language and its dissemination as widely as possible — has not been carried out.

In recent years there has been a noticeable rise of homophobic aggression and statements, yet — with the notable exception of an intervention by the Ombudsman in September 2012 regarding draft laws on "prohibition of propaganda on homosexualism" (see below), — the state authorities have not reacted in any way. Among local authorities and members of the national parliament, on the contrary, there has been an increasing level of homophobic rhetoric that is never condemned by representatives of governmental or presidential bodies.

Ukrainian authorities have not conducted any data collection and analysis on discrimination on the grounds of sexual orientation or gender identity. The respective data collected by Ukrainian LGBT NGOs has never been requested and used by Ukrainian government bodies".

## **(6)**

## Expanding the list of groups with higher risk to contract HIV<sup>13</sup>

The LGBT NGOs Council of Ukraine suggested to expand the list of most-at-risk groups, namely: to include into this list not only MSM who are traditionally — for more than 10 years — recognized in Ukraine to be one of the populations most vulnerable to contract HIV, but also **transgender peoples**, including transsexuals and intersexuals (hermaphrodites); women having sex women (**WSW**), as well as persons of woman gender with homosexual orientation (**lesbians**); women — sexual partners of the men having sex with men; men — sexual partners of the women having sexual intercourses with women.

The LGBT NGOs Council states in its letter to the Ministry of Health of Ukraine:

"Suggests paying attention to the fact that the variety of sexual practices as well as social and behavioral features of WSW (women having sex with women) as well as women with homosexual orientation, allows to make a grounded assumption that the risk to contract HIV/STI for WSW/lesbian community is significantly higher than in the general women's population.

Draws attention to the fact that recently key international agencies working in the sphere of HIV/AIDS control perceive **transgenders** as a separate social group, which requires specifically tailored prevention interventions.

Reminds that "The Global Fund Strategy in relation to Sexual orientation and Gender Identities (SOGI)" "urges all partners — especially **the** 

<sup>&</sup>lt;sup>12</sup> The final report on Ukraine's implementation of the Recommendation CM/Rec(2010)5 "Recommendation CM/Rec(2010)5 of the Committee of Ministers to member states on measures to combat discrimination on grounds of sexual orientation or gender identity" / Nash Svit Center. — K.: Nash Svit Center, 2012. — 74 p.

<sup>&</sup>lt;sup>13</sup> The Letter by LGBT NGOs Council to the Minister of health of Ukraine of September 13, 2012.

government [...] to consider more thoroughly [...] the vulnerability to HIV-infection for the peoples marginalized on the grounds of sexual orientation, gender identity and respective sexual behavior. The following populations groups are in the focus of attention: [...] men who have sex with men (MSM); transgender peoples, including transgenders, transsexuals and hermaphrodites; other sexual minorities, including women who have sex with women, especially in the countries with high HIV prevalence".

The Joint United Nations Programme on HIV/AIDS states in its "UNAIDS Action Framework: Universal Access for men who have sex with men and transgender people" that "structural factors, including sexual violence, may make lesbians and other women who have sex with women more at risk of acquiring HIV than would otherwise be thought".

Similar recommendations on the need to include homosexuals per se, WSW and transgender people into most-at-risk groups are included into other meaningful documents and surveys at the international, regional and national levels.

- Urgent LGBT NGOs Council's suggestions to the Ukrainian Government to implement the Recommendation of the Council of Europe's Committee of Ministers<sup>14</sup>
- 1. To include sexual orientation and gender identity into the list of grounds in relation to which discrimination is explicitly forbidden within the law on preventing discrimination in Ukraine.
- 2. To include sexual orientation and gender identity into the list of grounds in relation to which discrimination is explicitly forbidden in the Labor Code of Ukraine.

- 3. To introduce amendments into Article 74 of the Family Code of Ukraine ("The right to the property of a husband and wife who live as a family but their marriage is not registered or they are in any other marriage") with the goal to expand the scope of this Article to the same sex couples.
- 4. To introduce amendments into the Order No. 60 of February 3, 2011 "On improving health-care services for the individuals who need the change (correction) of sex", seeking to remove such counter-indications for the change (correction) of sex as:
  - having children aged under 18;
  - homosexuality, transvestism in the context of transformation of the sex role;
  - any sexual and perversion tendencies;
  - morphologic specific features that complicating (or making it impossible) the adaptation into the desired sex (hermaphroditism, disorders in the development of genitals);
  - impossibility to undertake endocrinology or surgery change (correction) of sex on the grounds of severe somatic diseases;
  - if a person who needs change (correction) of sex does not agree to the set of diagnostics and treatment procedures on change (correction) of sex recommended by the Commission.
- 5. To introduce amendments to the Procedure of examination applied to the individuals who need change (correction) of sex, adopted by the above mentioned Order, namely:
  - in Article 2.2. to remove the demand on in-patient laid mental health examination at a mental health facility; to include a clause on holding such an examination as an out-patient procedure;
  - in Article 13 of the Procedure to remove the clause on issuing a medical certificate on the change (correction) of sex only after the surgery being performed; to include a provision on an opportunity

<sup>&</sup>lt;sup>14</sup>Based on the final report on Ukraine's implementation of the Recommendation CM/Rec(2010)5 "Recommendation CM/ Rec(2010)5 of the Committee of Ministers to member states on measures to combat discrimination on grounds of sexual orientation or gender identity".

to issue the certificate thereof without a surgery.

- 6. To introduce amendments into Order of the MoH of Ukraine No. 479 of August 20, 2008 "On approving the list of the diseases preventing the person who lives with one of them is not eligible to adopt a child" by means of removing F64 code ("The disorders of sex identity" according to ICD-10) from Article 9 "Disorders of personality and behavior in adult age".
- 7. To include the topics of sexual orientation and gender identity into high schools' curricula and pedagogic universities' curricula as well as continuing education courses for high school teachers.
- 8. To issue an Order by the Ministry of Health of Ukraine on review of the current and suggested medical manuals and curricula, seeking to remove any definitions characterizing homosexuality (bisexuality) as a disorder, mental disorder, sexual perversion and/or suggesting "the treatment of homosexuality".
- 9. To include the topics of sexual orientation and gender identity into the curricula of the universities of law and police academies as well as continuing education courses for police officers.
- 10. To adopt the national middle-term and long-term action plan to implement other aspects of the CoE CM Recommendation.

### Chapter 8

# VIOLATIONS OF THE RIGHT TO HEALTH AT THE PENITENTIARY SYSTEM:

hat one should do if a person is imprisoned, his/her health condition is deteriorating from day to day, and there are no opportunities to provide the needed health care at a respective facility within the structure of the State Penitentiary System (SPS)? If a person is convicted pursuant to the court's ruling and the ruling on her/his guilt came into force, the procedure on releasing the person on the grounds of the health condition should be applied as prescribed by Article 84 of the Criminal Code of Ukraine. In this case and taking all circumstances into consideration, the court may issue an order on release and the person may be transferred to a regular hospital where she/he shall be provided with respective healthcare and continue the course of treatment.

But what about the individuals who have not been convicted yet by the court, what one should do with those who are just accused? In case they have a life-threatening disease, a court is not authorized to release them on the grounds of their health condition. Even if an individual suffers from non-delivery of healthcare and his/her life and health are endangered, yet the courts are not in a hurry to protect human rights: they usually adjudicate on more and more extensions of keeping the person in custody, opting not to substitute such measure of restraint as incarceration with alternative ones. Pursuant to Ar-

<sup>1</sup> The Chapter was drafted by Oleg Miroshnichenko, Volodymyr Bocharov-Tuz.

ticles 148 and 155 of the valid Criminal and Procedure Code (as of the time this article is being written), such a measure of restraint as keeping a person in custody constitutes an exceptional measure if all other measures are not efficient. One should recollect the case law by the European Court of Human Rights (Kharchenko vs. Ukraine). On February 10, 2012 the Court noted in the judgment that excessive use of the right to arrest is a systematic violation, and that Ukraine must take certain measures within six months to address these gaps.

But even after the ECHR provides its recommendations pursuant to Rule 39 of the Rules of the Court, which are mandatory for implementation by Ukraine as a High Contracting Party (Signatory) of the Convention on Human Rights and Fundamental Freedoms, we observe that urgent measures are not undertaken.

This was the problem with the case of *Anatoliy Tenchenko*, professor, former rector of Kryvyy Rih University:

This was the problem in the case of *Tamaz Kardava*, when the delays with providing urgent medical care resulted in a tragic death of a human being.

On April 24 the Court adjudicated one more judgment pursuant to Rule 39 of the Rules of the Court on taking immediate measures to provide medical care in relation to Vladyslav Viktorovych Velichko. As Olena Sapozhnikova, Ukrainian Hel-

sinki Human Rights Union defense lawyer, noted in her application to the Court:

"Since October 22, 2010 and till now the Applicant is in custody at Izmayil pre-trial detention center (hereinafter — SIZO), the address: 70 Suvorova street, Odesa oblast, 68601. Hence, he has been staying at a pre-trial detention center for two and a half years without medical care. His health condition is getting worse and arouses concerns. The concerns are that the diseases the Applicant lives with may result in a death of the individual thereof if the respective treatment is not provided to him. The applicant has the disability status, Group III, no family or relatives.

The applicant is diagnosed with: HIV-infection, clinical stage IV (AIDS), mouth and larynx candidosis, severe immunosuppression, generalized lymphadenopathy, varix dilatation of both shins. The letter sent from Izmayil SIZO on May 18, 2011 stated: "The health condition is deteriorating; there is a need in urgent start of ARV treatment at Odesa Regional AIDS Center".

«I request the Court to undertake urgent measures in relation to Velichko Vladyslav Viktorovych; particularly, to approach the Government of Ukraine with a suggestion to ensure proper examination and treatment by means of admitting him to a specialized healthcare facility where he could be provided with proper medical care."

Olena Sapozhnikova, defense lawyer:

"On April 24, 2012 the European Court of Human Rights pursuant to Rule 39 recommended the Government of Ukraine to provide urgent medical care to V. V. Velichko living with AIDS, IVth clinical stage, at a specialized healthcare facility, e. g. Odesa Regional AIDS Center. On May 16, 2012 Izmayil City and District Court ruled out on changing the measure of restraint from incarceration to release on his own recognizance. He was released from custody in the court's room. He has no relatives or family, therefore it is not clear how he will be able to approach Odesa Regional AIDS Center: it takes around 5 hours to get Odesa from

Izmayil by car; V. V. Velichko at least needs some

money to cover that distance. And the question

arises: how will they meet him at that Center? Will he be provided with medical care there?"<sup>2</sup>

As you may observe in the table, since 2008 the number of the individuals living with HIV at correctional facilities was increasing; it peaked in early 2012.

During 2012 the situation has crucially changed for the better in terms of access to ARV treatment for the prison inmates living with HIV<sup>3</sup>.

Thus, as of early 2012, 986 individuals were provided with ARV treatment. According to the Penitentiary Department's data, 1,100 inmates were on the waiting list to get ARV treatment.

The number of the people who are entitled to get ARV treatment but are not provided with medicines started to grow. There are some underlying reasons for that.

First, the number of the inmates, for whom ARV treatment is prescribed, has grown after they are examined at general penitentiary healthcare facilities.

Secondly, the supply size of ARV drugs at penal colonies is normally much below the necessary level. This is the result of the Penitentiary Department performs poorly in term of supplying the drugs to the prison healthcare facilities pursuant to the orders the facilities previously submit. For instance, if a prison healthcare facility orders 20 treatment courses, the Penitentiary Service supplies only 9–10 ones. The consequence is that the inmates who are entitled to get their prescribed ARV treatment face denials in providing the medicines by the prison healthcare authorities.

Here is one more example. As of early this year 20 persons needed ARV treatment badly just at one Chernihiv Penal Colony No. 44. The Colony did not have a supply of medicines to treat these

<sup>&</sup>lt;sup>2</sup> According to the articles by Andriy Didenko "How to save a human life?" and "The recommendations of the European Court have been executed; but has the human life been saved?!», http://hr-lawyers.org/index.php?id=1337276129.

<sup>&</sup>lt;sup>3</sup> The story was written by Volodymyr Bocharov-Tuz, "Network of the organizations working in penitentiary sphere".

inmates. The medication was available only for those who previously had started the treatment. The supply of the drugs was only for 3 months approximately. The similar situation could be observed in other colonies. E. g. as of late this year more than 10 inmates living with HIV were in the need of treatment at Kirovohrad Penal Colony No. 6.

Odesa-based "Sonyachne Kolo (Sunny circle)" NGO approached the "Network of the organizations working in penitentiary sphere" with a request for help in relation to the sick inmate who had been admitted to Kherson specialized hospital at the territory of the Colony No. 7:

"S. E., born in 1970, Kherson Oblast, Holoprystanska Penal Colony No. 7, CD count was 44 cells/ml of blood, viral load was 3 000 000, lymph nodes TB; the patient has been on TB treatment since September 2012. There are no ARV drugs at the facility, the inmate needs ARV treatment — but there is no medication". According to the recent reports, the situation is critical. Sonychne Kolo NGO is quite distant from Kherson AIDS Center. So far the NGO staff reached

an agreement to provide ARV treatment of the patient S. E. for one month. The most recent tests showed that S. E. CD4 count was 40 cells.

Pursuant to the Clinical Guidelines on Antiretroviral Treatment for adults and adolescents living with HIV, "every patient living with HIV should be screened whether they have Hepatitis C (HCV) by detecting antibodies to HCV (B-III). The positive outcome of the test must be confirmed by the presence of HCV ribonucleic acid in blood by PCR testing (A-II)". However, this requirement is "systematically" dropped. In late 2012 the situation improved a bit due to the fact that the Penitentiary Service received the humanitarian aid.

In 2012 there were reports on interruptions in ARV treatment courses for inmates: the breached continuity of ARV treatment. One of the reasons was the previously used practice of conducting ARV treatment at penitentiary settings of Ukraine. Thus, the inmates living with HIV were provided with drugs not only within the structure of the State Penitentiary Service, but also with the involvement of AIDS Centers' network. When an inmate receiving the ARV drugs at an AIDS Cen-

Morbidity and mortality rates at the Penitentiary Department's institutions<sup>4</sup>

Indicators	01/01/2004	01/01/2008	01/01/2009	01/01/2010	01/01/2011	01/07/2011	01/01/2012	01/07/2012
Number of the individuals at correctional facilities	191 677	149 690	145 946	147 716	154 027	157 866	154 029	152 076
Died	824	729	765	761	808	601	1 169	440
- Per 1,000 inmates	4.30	4.87	5.24	5.15	5.25	7.61	7.59	5.79
Suicides committed	41	54	40	44	44	28	59	32
- Per 1,000 inmates	0.21	0.36	0.27	0.30	0.29	0.355	0.383	0.42
Patients with active TB	9080	6195	6079	5667	5486	5393	4822	5007
- Per 1,000 inmates	47.37	41.4	41.65	38.36	35.62	34.2	31.3	32.9
PLWH	1917	5017	5073	6069	6020	6438	6910	6347/ -8.15%
– Per 1,000 inmates	10.0	33.5/ +15%	34.8/ +3.6%	41.1/ +18%	39.1	40.8	44.9	41.7

<sup>&</sup>lt;sup>4</sup> Prison Portal http://ukrprison.org.ua/statistics/1344593701

ter was transferred from one corrections facility to the other one, he/she experienced problems with access to treatment. The situation was the most frequent when the inmate was transferred to the penal colonies located at long distances from AIDS Centers; this resulted in obstacles for timely transfer of the drugs.

This practice is in the breach with the Rules adopted on September 5, 2012; the Rules set the regulations on administration of ARV treatment. These Rules clearly outline the roles of all parties involved and responsible for administering ARV treatment at penitentiary settings.

Besides, in 2012 some problems occurred with providing specific treatment regimens for the inmates living with HIV. In June 2012 ARV treatment regimen comprising "Truvada" drug was prescribed for Dmytro (the convicted person) at an interregional prison hospital. The medication's supply was for 3 months. However, the colony, where Dmytro was serving his term, did not have this drug available. Seeking to prevent the skips in the drugs' uptake, the decision was taken to adjust the ARV treatment regimen for Dmytro. As a consequence, it was the regional AIDS Center that started to provide Dmytro with a new ARV treatment regimen course.

Mykhaylo M., the inmate, was transferred from the Penal Colony No. 97 to the interregional healthcare facility at the Penal Colony No. 124 where ARV treatment was prescribed for him. Upon being provided with a supply of medicines, he was immediately transferred back to the Penal Colony No. 97. This step violated the regulations set forth by the HAART clinical guidelines: "The key indication for the decision on starting ARV treatment is the CD4 count. The decision on prescribing ARV treatment should be based upon the findings of the two independent CD4 tests conducted with an interval of 14-28 days between them to exclude the probability of lab tests error and other reasons to discard the indication (e. g. intercurrent diseases)".

When the inmate stayed at Donetsk pre-trial detention center, according to the report by the inmate he went on hunger strike due to the se-

vere side effects of ARV treatment. He demanded the opportunity to be treated at the in-patient facility of the interregional hospital until the moment his side effected subsided.

In 2012 the problem with availability of sufficient number of healthcare professionals specialized in communicable diseases at correction facilities remained acute. The insufficient number of these professionals resulted in limited access of the inmates living with HIV to the services of such doctors.

The interregional hospitals within the structure of the Penitentiary Service and the facilities where the communicable diseases doctors from regional (city) AIDS Centers consult their patients constitute exceptions. However, it is more frequent a case when the colonies located far from the AIDS Centers do not have an opportunity to practice consultations by a doctor in communicable diseases.

Besides, the administration of a correction facility is not authorized to introduce new positions into the staff list of the prison hospitals.

Both the persons sentenced by the court and the inmates staying at the places of imprisonment very often cannot manage to get quality medical examination. The Penitentiary Service takes measures to modernize the medical equipment; however, these measures and the pace of the equipment's modernization are overtly insufficient.

In 2012 the complaints were filed regarding the quality of TB testing. In early 2012 Ivan K., the inmate, underwent an examination at the general prison hospital at Dnipropetrovsk pretrial detention center. The recommendation was done on the need to prescribe ARV treatment for him. Upon the recommendation being done, the inmate was transferred back to the penal colony. In less than a month he died, because the healthcare professionals at the general prison clinic overlooked his extrapulmonary tuberculosis. He was diagnosed with tuberculosis at the TB hospital within the structure of the MoH, when the patient was admitted there on the grounds of his abrupt worsening of the condition.

There were some more complaints submitted by inmates regarding the lack of access to medicines. The limited supply of medicines available at prison healthcare facilities opens the opportunities for corruption. For example, Mykola L., approached the prison clinic with a request to remove a tooth. The dentist used "Lidocaine" analgesic, which is quite weak in managing the pain in the course of tooth's removal. One should note that the dentist had "Ultracaine" drug, which is much better to treat the pain. But the doctor extorted a pack of cigarettes as a "charitable donation" in exchange. The inmates complained about the lack of other drugs: liver protectors, fluconazole (used to treat opportunistic diseases).

The paradoxical situation occurred: "Network of the organizations working in penitentiary sphere" was approached on the issue of the prevention of mother-to-child transmission of HIV with a pregnant HIV positive woman who was kept at a SIZO (pre-trial detention center). Pursuant to clinical guidelines, she was entitled to start the respective treatment. But soon she was sentenced and transferred to Melitopol women penal colony for minors. The problem was that this institution did not feature any facilities to accommodate a convicted mother with a child. The partial resolution for the problem was identified: the convicted person stays at the SIZO currently.



#### Recommendation

- 1. To determine (by adopting respective policies) legitimate grounds for a court to choose a measure of restraint in criminal proceedings, taking into account the state of health of the criminally prosecuted person.
- 2. To introduce the efficient mechanism of changing a measure of restraint on the grounds of the health condition of the criminally prosecuted person.
- 2. The State Penitentiary Service should design a procedure of predicting the adequate supply of medicines, particularly ARV drugs, at health clinics of the correctional facilities, taking into account the probable number of patients, including those living with HIV.
- 3. The State Penitentiary Service should ensure continuity of the ARV treatment during the transfers of inmates from one correctional facility to the other one.
- 4. The State Penitentiary Service should devise a procedure (standing orders) for communicable diseases doctors to provide targeted treatment for the inmates living with HIV/AIDS (staff list, planned visits to examine patients).
- 5. The State Penitentiary Service should develop a specific procedure for keeping in custody of the detained or convicted HIV positive mothers with children.

### Chapter 9

### **ROMA: ACCESS TO HEALTHCARE SERVICES**

ccording to Ukraine's census, 47,600 Roma live in Ukraine. 14,000 Roma (1.1% of the region's population) live in Transcarapthean oblast (Uzhgorod, Beregovo, Vynohradovo districts and in the cities of Uzhgorod and Mukachevo), 4,100 — in Donetsk oblast (0.1%), 4,000 — in Odesa oblast (0.2%), 4,000 — in Dnipropetrovsk oblast (0.1%), 2,200 — in Luhansk oblast (0.1%), 2,300 — in Kharkiv oblast (0.1%). The rest of oblasts and the cities of Kyiv and Sevastopol feature Roma populations ranging from 100 to 1,000. According to the estimates by Roma NGOs, from 200,000 to 400,00 Roma live in Ukraine.

## 1 The data collected by Roma Health Mediators in 2011–2012

In 2010–2012 *Ciricli*, Roma women international charitable organization, was implementing the project "Improving the situation with Roma health in Ukraine through the launch of Roma Health Mediators Program" with the support of the International Renaissance Foundation. In particular, the project entailed the work of mediators — **Roma Health Mediators** — in Roma communities located in 12 Ukrainian regions.

The social status of most Roma community members is low; therefore they cannot afford

<sup>1</sup>The information for the chapter was provided by Yuliya Kondur, Ciricli, the international charitable Roma women foundation; the recommendations were provided by Nataliya Kozarenko.

buying medicines for them or pay for the course of treatment. Lack of funds is a barrier in terms of having documents issued for them or to pay fines. In the latter cases health mediators are not able to help, because there are no funds for these purposes within the project's budget.

One of the key problems is the problem with housing. Almost 80% of Roma have houses, which are below the appropriate dwelling standards, are not compliant with sanitary and hygiene standards. These factors contribute to spread of diseases.

"Most Roma families live in slums, with no water supply, with no sewage facilities, even with no floor". The life is especially hard in winter.

Roma communities are deeply affected by mass unemployment. The lack of proper education hinders in the way to find any job, save for a highly paid one.

The data on "Improving the situation with Roma health in Ukraine by means of implementing the Roma Health Mediators Program" carried out with the support by the Council of Europe in 2010–2012

"Roma Health Mediators" project involved activities in 13 communities in 5 regions of Ukraine: Odesa, Lviv, Transacarpathian, Donetsk (Makiyivka) and Kyiv region. 14 representatives of Roma communities or the persons, belonging to other

nationalities, but enjoying trust with Roma were selected and trained. Their performance was assessed in compliance with the procedure devised by the Council of Europe within the frame of ROMED program as well as via communicating with Roma whom they were working and the local authorities.

The cooperation with a group of experts was institutionalized for further successful implementation of the project: they represented a set of governmental bodies of Ukraine (Ministry of Health, Ministry of Education and Science, Ministry of Labor and Social Policy, Ministry of Justice, Ministry of the Interior, the Institute of Legislation of the Parliament of Ukraine, the Migration Service as well as regional local government bodies). Their functions include issues of delivery of healthcare and social services for adults and children, services on registration and support in drafting respective policies. Each member of the working group was providing expert and technical support for the project, entailing:

- 1. National policies analysis laws and policies in the area of healthcare, labor and social policy, state registration of persons, activities of the bodies and agencies providing services in the sphere of family, protection of children's rights, local government bodies' efforts;
- 2. Analysis of the opportunities and searching the ways to adapt the Romanian experience on realization of Roma Health Program;
- 3. Analysis of the reports submitted by Roma mediators and summarize their problems to identify further areas for work and recommendations to address the problems;
- 4. To develop suggestions on formalizing the status of Roma mediators (designing Regulations on mediator's work) and including it into the list of professions:
- 5. To provide urgent counseling advice for mediators on their everyday issues regarding healthcare services, social issues, registration and passport related problems, etc.

The experts' group members worked at during the visiting sessions and at the training

courses for mediators conducted to deepen the understanding of the program's objectives and the role of mediators in its implementation.

## The following documents were signed to ensure efficiency in the activities:

- 1. On June 1, 2011 the agreement with the Transcarpathian Region Employment Center was signed.
- 2. In 2011 the common action plan was designed in cooperation with Transcarpathian and Odesa oblast administrations. Berehovo District Council members adopted the Common Action Plan to improve the situation of Roma.
- 3. On February 14, 2012 the Memorandum on cooperation was signed by the state-run "National TB Control Center affiliated with the Ministry of Health of Ukraine and Ciricli Roma Women International Fund.
- 4. Roma mediators were co-opted as members of the Public Councils at the local city councils in Berehovo, Odesa, Donetsk and Kyiv. The cooperation with the Coordination Council on HIV/AIDS and TB issues was established; Roma health mediator became the member of the Council. Roma mediators launched cooperation with passport issuing offices, healthcare departments, social services, city and oblast state administrations.

### UNICEF support made it possible to develop information materials (deliverables) for Roma communities on the following topics:

- Health of a mother and a child,
- Early (up to 5 years old) child development,
- Reproductive health,
- Breast cancer.

Since 2012 7 oblasts were added to the project; 50 Roma Health Mediators were trained. So, they started to work in 12 oblasts of Ukraine: Odesa, Lviv, Transcarpathian, Donetsk, Kyiv, Zaporizhya, Kherson, Kharkiv, Dnipropetrovsk, Luhansk, Kirovohrad and the Autonomus Republic of Crimea. Within 2 years 12 round tables were conducted in 12 regions to establish cooperation between health mediators and government bodies' representatives.

## In 2011–2012 the following activities have been completed:

1. The mediators visited **49,225** persons in **12** pilot regions.

The key Roma health problems were identified and the respective support was provided:

- 2. **5,901** Roma were referred for further examination by health practitioners.
- 3. X-ray testing was organized and provided for **2,223** individuals; **133 persons** were diagnosed with TB as a result of X-ray tests; they were referred to the facilities to get further treatment.
- 4. **2120** Roma children were vaccinated; 875 focus groups' meetings were held; the topics were "Vaccination is mandatory", "How to prevent tuberculosis", "The importance of an indepth medical examination", "Personal and domestic hygiene".

According to the data in the reports submitted by Roma Health Mediators, Roma's most frequent diseases include:

- Communicable diseases,
- cancer,
- endocrinonology-related diseases,
- cardiovascular diseases,
- viral ones,
- stomach diseases.

Summing up, one may conclude that Roma in Ukraine currently do not enjoy access to healthcare services in equal parts with the average population. The health related problems in Roma communities are systematic. The key underlying reasons for high diseases' prevalence among Roma in Ukraine are directly related to the lack of regular medical examinations, proper and timely medical care and the traditional lack of trust among Roma and non-Roma healthcare

professionals, lack of money and incentives for Roma to consult a doctor.



#### Recommendations

- 1. To ensure delivery of efficient legal aid for Roma in cases of discriminatory practices against Roma in the spheres of education, employment, housing, healthcare, social services and access to civil rights.
- 2. To provide all citizens of Ukraine, including Roma, with all personal and other documents vital to realize fundamental civil, political, and social and economic rights. To develop the programs aimed at providing all Roma who actually live on a specific territory with housing registration; to make sure that local government bodies do not deny Roma in providing them with registration documents.
- 3. To promote the corrections to be introduced into the current statistic data regarding social services delivery for Roma, including healthcare services and social services.
- 4. To legitimize the institution of Roma Health Mediators at the state level by means of developing and adopting the National Roma Health Mediators Program.
- 5. To establish cooperation of Roma communities' leaders and representatives of healthcare departments in each region and Roma settlements.
- 6. To design and introduce comprehensive training programs for healthcare officials, healthcare facilities' staff in order to ensure their awareness of international and national standards prohibiting discrimination and application of these standards in their activities, in particular to guarantee their proper discharge of duties in terms of protecting citizens of Ukraine from discrimination.

### Chapter 10

### **VACCINATION: A RIGHT OR A DUTY?**

eeking to ensure epidemic safety of Ukraine and prevention of the infections managed by means of specific prophylaxis; in compliance with Article 27 of the Law of Ukraine "On ensuring public sanitary and epidemiological safety", Articles 1, 12 and 13 of the Law of Ukraine "On protection of the population from communicable (infectious) diseases" and the Law of Ukraine "On adoption of the National Program on immunoprophylaxis and protection of the population from the infectious diseases for 2009–2015" — on September 16, 2011 the Order No. 595 of the MoH of Ukraine "On the procedure of conducting prophylaxis vaccinations in Ukraine and the control over the quality and handling medical immunobiological medicines" introduced the new procedures:

- The schedule of prophylaxis vaccinations in Ukraine.
- The procedure on organizing and holding prophylaxis vaccinations and tuberculin skin tests.
- The instructions on organizing epidemiological surveillance over the adverse developments upon the use of vaccines, toxoids and tuberculosis allergen.
- The Regulations on first urgent aid in cases of adverse events after immunization when vaccines, toxoids, and TB allergen are used in cases of hospitalization or lethal event.

- The Regulations on the urgent action team in cases of adverse events after immunization when vaccines, toxoids, and TB allergen are used in cases of hospitalization or lethal event.
- The Procedure of selling vaccines and toxoids through pharmacies network.
- The Procedure on ensuring proper conditions for storage, transportation, acceptance and keeping account of vaccines, toxoids, and TB allergen in Ukraine.

## 1 Anastasia' case

Unfortunately, still one may observe the cases putting under doubt, firstly, the safety of prophylaxis vaccinations for children and the need in conducting vaccinations in general.<sup>2</sup>

"Anastasia lost her younger son a month ago. The young Simon died in her hands in four days after the vaccination. According to the official version of Odesa healthcare professionals, the cause of death is "the neoplasm of unrecognized character of the other specified localizations (heart)". The doctors consider the issue to be closed: in their opinion, this one more death of a baby is not related to vaccination. But the mother considers it to be her duty to find out what was the cause that killed her younger son, her maternal duty before the elder son, Ilya, 4 years-old.

<sup>&</sup>lt;sup>1</sup>The recommendations provided by pediatricians Yevhen Komarovsky and Andriy Pen'kov were taken into consideration while this chapter was being drafted.

<sup>&</sup>lt;sup>2</sup> According to the story "Indifference by schedule: what killed Odesa child?», Sergey Dibrov, 03/21/2012, http://www.privivok.net.ua/

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— That vaccination was the second in the course of diphteria and tetanus toxoids and pertussis vaccine, — Anastasia reports. — A year ago the child had bronchitis with asthma component. The boy was being examined by doctors for two months every day. Certainly, the various tests were conducted, his lungs and heart were checked. No other abnormalities were detected. Me and my husband managed to find the rare necessary medicines and returned the child to life. The diseases retreated and in a year the doctors reminded us that it was high time to continue with the interrupted vaccination course.

The parents provided the best care for their child one could find. The second vaccination was conducted by the most expensive vaccine — Belgian "Infanrix-Gexa". It is considered to be most safe, it includes all six components and enables doing all vaccinations related to certain age within the frame of one visit to a doctor; according to a popular opinion, it relieves the pressure over the body and mental composition of a child.

Later when her pain of the heavy loss abated a bit, Anastasia found out that the disaster that happened with her child was fully in line with the symptoms of serum sickness that may develop, inter alia, "as a result of prophylaxis vaccinations in young age". She was waiting for the histology tests' findings. She had hopes that forensic examination report would provide answers to her questions. Was the child's disease lethal? Was the neoplasm a malignant one? Why was the neoplasm diagnosed — remembering that the child was under permanent medical observation? Could one say that the predisposition to allergy, which allegedly has the genetic roots, was the real cause of death? And the most important question: what should she do to keep her elder son, Ilya, safe?

Alas, Anastasia was not provided with the answers to her questions. Three weeks of laboratory tests had nothing to add to the primary diagnosis of "the neoplasm of unidentified character".

After Anastasia submitted an official request to provide her with the findings of the forensic examination, different government bodies started to get of rid of her by referring from one place

to the other. The experts justify their silence by "the investigation's secrecy regime" and refer her to the prosecutor's office. The prosecutors report that no investigation has been launched and suggest her approaching the experts. After going several circles, Anastasia has solid grounds to suspect that either no tests were conducted or the experts have something to hide. For example, the real cause of death of a child.

Anastasia is adamant to learn the truth. If the cause of death of her younger child was serum sickness, and if there is a predisposition, her elder son should be vaccinated with special care. Namely: special scarification pre-tests should be conducted as well as pre-vaccination rehabilitation for a child; vaccination should be administered in compliance with a special procedure. It goes without saying that healthcare professionals are not willing to undertake these precautions, but, at the same time, the mother faced already some demands and threats: "your child will not be allowed to attend a nursery if vaccinations are not administered to him".

On legislative framework: The Regulations on organizing and holding prophylaxis vaccinations and TB diagnostics in compliance with the Order No. 595 of September 16, 2011 "On the procedure of conducting prophylaxis vaccinations in Ukraine and control of the quality and handling of medicinal immunobiological drugs" include provisions, particularly, that a medical examination of minors before a vaccination or TB diagnostics procedure must incorporate:

"Receiving an informed consent and conducting an assessment of the health condition of a child by one of the parents or other legal representative in relationship with vaccination or TB testing, approved by the Order No. 1086 of 12/31/2009 registered by the Ministry of Justice of Ukraine by the act No. 594/17789 (Form No. 063-2/0) on August 2, 2010".

Medical counter-indications to vaccinations for a specific person shall be determined by the Vaccinations Commission to be set up by a healthcare facility internal order pursuant to the List of medical counter-indications to prophylaxis vaccinations determined by the same order. If there are complicated and controversial problems related to counter-indications to vaccinations, the vaccination commission at a regional, city or a republican healthcare facility shall be set up by the Order of the Healthcare Department of respective regions (oblasts), the Autonomous Republic of Crimea, Kyiv and Sevastopol City.<sup>3</sup>

The fact of refusal from vaccination with a special notice one a patients' debriefing done by a health-care professional on the consequences of the refusal thereof shall be formalized by filling in the form No. 063-2/0. It shall be signed by an individual (if a minor is vaccinated — by his/her parents or other legal representatives who substitute them) and a respective healthcare professional; the information on the refusal shall be provided for the local Sanitary and Epidemiologic Service office<sup>4</sup>.

## 2 Litigation efforts aimed at protecting the right to freely choose treatment

PERSON\_1 filed an administrative suit with a request to recognize the official document on an individual action enacted in a policy by a person while discharging her duties to be invalid and to cancel it; the lawsuit was filed to Pervomaysk City Court in Luhansk oblast. On March 23, 2012 PERSON\_1 received an order No. 39 of March 22, 2012 by PER-SON\_3, the principal of "Sonechko" nursery No. 39 (hereinafter — the Defendant-2); the order was to suspend (since March 23, 2012) the attendance of "Sonechko" nursery by a minor son of PERSON\_4; the PERSON 4 represented the interests of the minor in compliance with Article 56, part 4 of the Administrative Procedural Code of Ukraine. The Order was issued on the grounds of "The Submission on suspending from work or other activity" No. 23 of March 13, 2012 (hereinafter — the Submission) by O. V. Yershova, Pervomaysk City Chief State Sanitary Doctor (hereinafter — the Defendant) on suspending the attendance of "Sonechko" nursery by the minor child of PERSON\_4, the child was not TB

vaccinated; the Submission was to enact suspension since March 19, 2012 — until the child was supposed to be TB vaccinated.

OnMay 16,2012 Pervomaysk City Court of Luhansk Oblast ruled out: To partially satisfy the Administrative lawsuit filed by PERSON\_1 to Olena Vasylivna Yershova, Pervomaysk City Chief Sanitary Doctor, on recognizing the individual action of the official enacted in documents to be invalid an to cancel it. To recognize the submission No. 23 of 13 March, 2012 on suspending the attendance of "Sonechko" nursery by the minor child of PERSON\_4 by Olena Vasylivna Yershova, Pervomaysk City Chief Sanitary Doctor to be invalid — INFORMATION\_15.

# 3 The Departments of Education and Science at the Regional State Administrations fail to implement the explanations, decrees and other official acts

A year before the administrative lawsuit described in the previous chapter, namely, on May 25, 2011 (just a year before the adoption of the mentioned judgment by Pervomaysk City Court of Luhansk region) the Ministry of Education, Science, youth and sports of Ukraine disseminated an official letter<sup>6</sup> to the regional departments of education and science, Crimean Republican Ministry, Kyiv and Sevastopol city departments; the letter was entitled "On the procedure of enrolling a child to a pre-school education facility; it goes:

"The refusal of a principal of a pre-school education facility to admit a child to a facility on the grounds of missing prophylaxis vaccinations shall be in a breach of the valid laws and policies of Ukraine. If there are medical certificates of the specific format available, where an authorized doctor certifies that the child may attend a pre-school education facility, then the principal shall be obligated to admit the child to the facility".

<sup>&</sup>lt;sup>3</sup> The Order of the MoH No. 595 of 09/16/2011.

<sup>&</sup>lt;sup>4</sup> The Order of the MoH No. 595 of 09/16/2011.

<sup>&</sup>lt;sup>5</sup>The text of the Court's judgment and the justification section may be found at http://reyestr.court.gov.ua/Review/ 24430897?Liga=True

<sup>&</sup>lt;sup>6</sup> Letter No. 1/9-389 of 05/25/2011

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#### On legislative framework:

The Order No. 434 of November 29, 2002 of the Ministry of Health of Ukraine "On improving the out-patient and polyclinic care for children in Ukraine" regarding preparation of children within a pediatrician's district for further attendance of pre-school and general school facilities goes:

- The issues on attendance of a pre-school education facility by children whose parents refuse from vaccinations shall be determined by the medical and counseling commission.
- The issue on attendance of a general education facility by the children who have not been vaccinated in compliance with the schedule of vaccination should be addressed individually pursuant to the decision by the doctors' commission with the involvement of the epidemiologist of the local sanitary and epidemiology office in compliance with Article 15, chapter III of the Law of Ukraine "On protection of the population from infectious diseases".



#### Recommendations

#### O To the Ministry of Healthcare

- 1. To improve the awareness raising and research interventions regarding the purpose of prophylaxis vaccinations.
- 2. To provide data on development and spread of the diseases the vaccinations seek to control; particularly, to monitor and record the data on morbidity of the vaccinated and non-vaccinated persons.
- 3. To provide universal access to these data and post analytical articles by leading experts on these issues.
- 4. To improve the police framework of doctors' councils and commissions, which are set up pursuant to the Order of the MoH of Ukraine No. 434

of November 29, 2002, with the purpose to ensure transparency of the decision-making process.

5. To conduct assessment of the epidemiologic situation in Ukraine and the vaccines' quality with the involvement of independent — or international — experts.

#### To the Ministry of Education, Science, Youth and Sports of Ukraine

- 1. To inform the regional departments of education and science, Crimean Republican Ministry, Kyiv and Sevastopol city departments about the contents of the letter by the Ministry of Education, Science, Youth and Sports No. 1/9-389 of 05/25/2011 "On the procedure of enrolling a child to a pre-school education facility" that it states "the refusal of a principal of a pre-school education facility to admit a child to a facility on the grounds of missing prophylaxis vaccinations shall be in a breach of the valid laws and policies of Ukraine, or to adopt a new policy.
- 2. To institute monitoring of the respect to the valid laws and policies of Ukraine on preventing possible refusals by heads of educational facilities to admit children to their institutions if the children have not been vaccinated.
- 3. In cooperation the Ministry of Health to implement the awareness raising and research interventions regarding the purpose of prophylaxis vaccinations.

#### O To civil society organizations

- 1. To document the facts of probable reactions or complications that occurred after prophylaxis vaccinations have been administered.
- 2. To demand from the government of Ukraine to conduct independent expert surveys for each fact of the alleged breach of the valid policies regarding the quality of medication, namely vaccines, their storage conditions and other factors that have led to complications upon administering vaccinations.

Наукове видання

### **HUMAN RIGHTS IN HEALTHCARE** — 2012

Human rights NGOs report on respect for the right to health in Ukraine

(англійською мовою)

Відповідальний за випуск *Андрій Роханський* Редактор *Андрій Роханський* Комп'ютерна верстка *Олег Мірошниченко*