Visit Report Donetsk Ukraine

July 24th – 28th July, 2007

Table of Content

Introduction 3

Situation of the HIV Epidemic in Ukraine and the Donetsk Province 4

Medical Care Structures for HIV-positive Patients in the Oblast and City of Donetsk 5

The Policlinics 6

The Regional AIDS-Centre (Regional Policlinic) 7

The Central HIV Laboratory 9

The HIV/AIDS Ward 11

House und Rooms: 11

Distribution of Rooms/ Patient rooms: 12

Admittance of Patients and Visitors: 13

The Team: 13

Catering: 14

Invasive and diagnostic operations: 14

Diagnostic equipment: 15

Consultants: 15

Medical Care Structures for Tuberculosis Patients in Donetsk Oblast 16

Preliminary remark: 16

TB Health Centre, TB Clinic of Donetsk City and TB Health Centre of Donetsk Oblast 17

Medical Substitution Maintenance Therapy for IDU 20

Preliminary remark: 20

Outpatient Substitution Therapy at the Regional Narcological Health Centre 20

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Introduction

Since 2001 different professions (doctors, nursing staff, social workers) of the *Vivantes Auguste-Viktoria* Clinical Centre, the *Felix Pflegeteams e.V* (patient care team) and *Berliner AIDS-Hilfe e.V*. (Berlin AIDS Federation) have been involved in initiatives to fight the HIV epidemic in Eastern Europe, and especially in the Ukraine. Ever since the situation of HIV-infected people in Ukraine has been the subject of various public discussions on the »HIV Dialogue« conference.

In addition to that, medical and nursing staff co-initiated with *Connect plus e.V.* an exchange programme (»Medi & Care«) with different specialists/qualified medical employees from Russia, Moldavia, Poland and Ukraine. Moreover they participated in the development of WHO guidelines for the Commonwealth of Independent States (CIS). And last but not least, doctors, health care as well as social workers and psychologists are involved in providing clinical training, technical assistance, and capacity building for doctors, nurses and social workers in the CIS within the framework of the Knowledge Hub (*The Regional Knowledge Hub for the Care and Treatment of HIV/AIDS in Eurasia*).

Those initiatives triggered a discussion that developed between 2005 and 2006 on further commitment in the CIS. Within the scope of this perspective debate, representatives of the different professions came together and agreed upon focusing work on one area, thus striving to use the individual resources more effectively and to ensure evaluable sustainability of the initiatives. A more intensive cooperation with a regional/local initiative would be desirable for this purpose.

At the same time the health care staff of the *Vivantes Auguste-Viktoria Clinical Centre* developed in cooperation with the *Felix Pflegeteam* and CARITAS Ukraine, *inter alia*, a home care training programme in Donetsk for the outpatient care of people living with HIV/AIDS (PLWHA). The cooperation project is locally implemented and

evaluated as a training course. The project is funded by the *Robert-Bosch Foundation*.

In 2005 the Berlin-based journalist Karsten Hein accomplished to make contact with the heads of the Donetsk regional AIDS centre, Doctor Nikolai Grazhdanov and Doctor Keikawus Arasteh, during a visit to Donetsk while researching for his documentary film »On the Edge – Six Chapters about AIDS in Ukraine«. Subsequently Doctor Arastéh, Susann Kowol and Inge Banczyk visted the Donetsk AIDS centre in January 2006, where they agreed upon cooperation with the *Vivantes Auguste-Viktoria* clinical centre, the Berlin *AIDS-Hilfe* and the regional Donetsk AIDS Centre. Goal of the cooperation is an immediate and practical exchange as well as the transfer of knowledge regarding clinical, therapeutic and care options in the treatment of HIV patients.

Within the scope of this cooperation we, that is, Viola Winterstein (MPH) and myself, Christoph Weber, (physician) realised an assessment visit from July 24th to July 28th 2007. Objective of this visit was to capture the local/regional infrastructure and to determine current diagnostic and therapeutic possibilities for the care and treatment of HIV-associated diseases.

Situation of the HIV Epidemic in Ukraine and the Donetsk Province

With 48 million inhabitants, Ukraine belongs to the more heavily populated countries of geographical Europe. In Donetsk oblast about 10 % of the total population live on 4.4 % of the Ukrainian territory. According to EuroHIV (*HIV/AIDS Surveillance in Europe*: End-year report 2005 No. 73) the number of registered HIV new infections in the Ukraine has more than doubled between 2001 and 2005 (2001: 125 million; 2005: 243 million). With 1.7 %, HIV prevalence in Donetsk oblast, the rate ranges above the national average of 1.4% (WHO, 2003).
Like in all other regions of Ukraine, the percentage of people who became infected with HIV as injection drug users (IDUs) is especially high in Donetsk, too. Yet the way

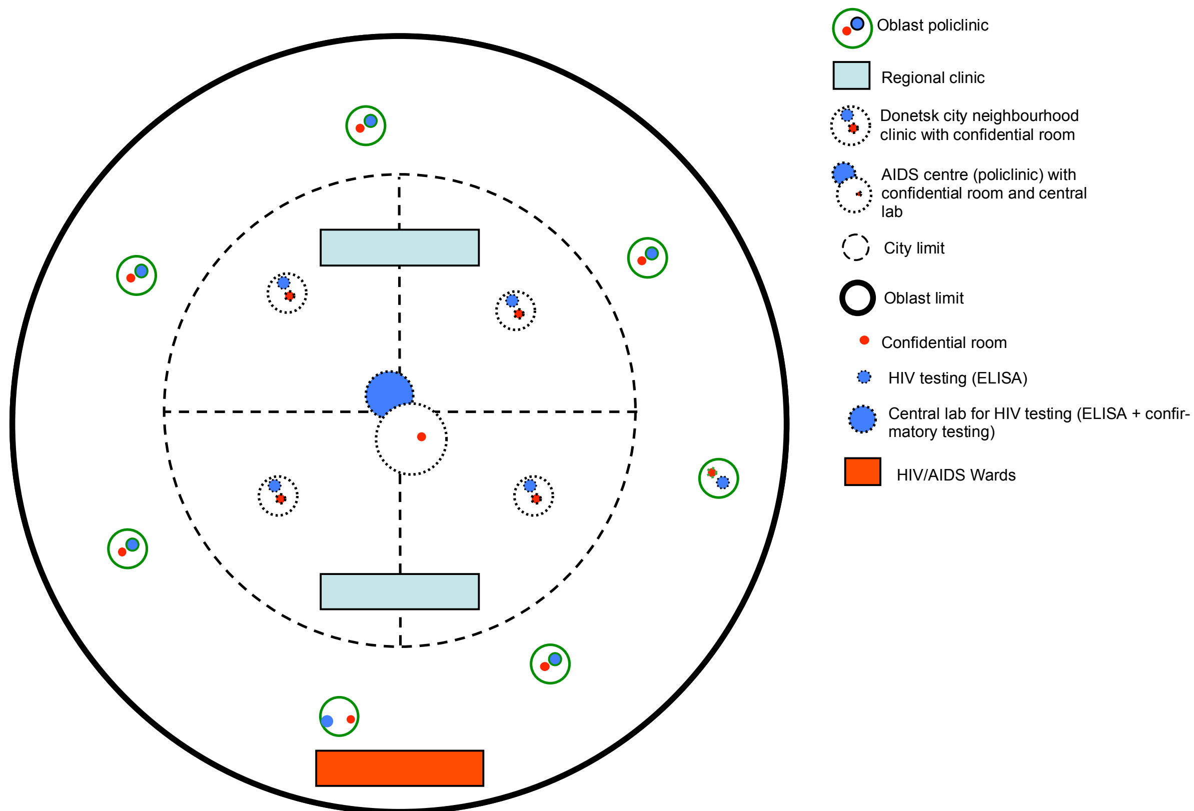
of transmission seems to have changed during the last years. Whereas during the 1990s needle-sharing had been the main cause, a new study (Scherbinskaja et al., 2006) indicates that in 2006 more than 55-60 % of the new infections were due to unsafe sex with an infected drug user.

Hence there is increased evidence that the percentage of HIV-infected people of other risk groups is constantly growing. According to an investigation by the Ukraine Ministry of Health (Ukraine Ministry of Health et al., 2006b) 34.2 % of the sex workers in Donetsk oblast are infected with HIV. However, the HIV prevalence among men who are having sex with men (MSM) remains unclear, since there are only few investigations about it. Donetsk is considered besides Kiev and Odessa a MSM centre; thus the few existing samples from Mykolayiv and Odessa (approx. 28 % of the MSM are HIV-infected according to the Ministry of Health Ukraine et al., 2006a) seem quite applicable.

Medical Care Structures for HIV-positive Patients in the Oblast and City of Donetsk

The medical care infrastructure for HIV-infected people in Donetsk oblast includes the whole province with the city of Donetsk, and follows the principle of centralised local utility sectors, in the style of existing policlinics. The are two ways to be admitted into the system:

1) A patient wants to get tested for HIV. In general this can also be done anonymously.
2) Due to the fact that a patient either is at risk, or for medical considerations HIV testing is suggested to him. If the patient doesn't expressly ask for anonymousAll data collected will be transferred to the regional AIDS centre.



The Policlinics

There are four policlinics in Donetsk City that are in charge of primary care of the people infected with HIV. Additionally six policlinics are area-wide distributed in the whole Donetsk oblast. All of the policlinics are equipped with a so-called confidential room. The confidential room is the place where a patient is attended by an infectiolo-gist and HIV testing can be performed. Each of those local policlinics has laboratories attached, equipped to do ELISA HIV tests. The confirmatory test is always performed at the central lab of the AIDS Centre.

If a patient is tested HIV-positive, he will receive an initial examination consisting of a physical exam, laboratory-chemical haemogram and clinical chemistry, HSV IgG, CMV IgG, EBV IgG, Toxoplasmosis IgG-avidity as well as CD4 count test. Based

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upon the test results, the stage of the disease is determined according to WHO guidelines, and the patient will be summoned for check-ups every three or six months. In doing so, the local policlinic remains the primary care centre.

It frequently occurs that a patient does not feel comfortable in his allotted policlinic, or that the does not want to contact to the regional policlinic for fear of being discriminated. Switching to an adjacent care centre is impossible; patients will be turned away. It is, however, possible to be attended in the regional AIDS centre or the attached policlinic respectively. In return some of the patients have to put up, for instance, with long distances and ensuing transportation expenses (bus, train, taxi etc.). Until recently the distribution of ART had been confined exclusively to the AIDS Centre. Since May 2007 the ART provision for HIV patients has been reallocated to the responsible policlinics.

The Regional AIDS Centre (Regional Policlinic)

The regional AIDS centre is composed of three departments: the policlinic, the epidemiological database and the central laboratory (lab). As a superior centre it serves exclusively to the care of HIV patients. Altogether ten doctors are working in the policlinic: a paediatrician, six infectiologists, a dermatovenerologist, and two stomatologists (diagnosing and treating diseases of the mouth). In doing, so the policlinic takes care of the HIV patients of the neighbourhood, plus everybody from the oblast and the city of Donetsk, who wishes to be attended at the centre.

ART is available according to the national protocol:

- Efferven (EFV) by Rambaxy
- Nevimune (NVP) by Cipla

- Diovir (AZT/3TC) by Cipla

- Lamivir (3TC) by Cipla
- Zidovir (AZT) by Cipla
- Videx (ddI) capsules by BMS
- Stavir (d4T) 30mg and 40mg by Cipla

- Kaletra (LPV/r) by Abbott stored in the fridge

According to the interviewed doctor, the ART is given free to the patients, whereas accompanying drugs like e.g. the anti-diarrheal Loperamid or Metoclopramid to relieve the ATR side-effects like, for instance, diarrhea or nausea, have to be purchased by the patient. They are merely prescribed and not available at the policlinic. Though Gabapentin to treat peripheral neuropathy is in stock, it is not sure, if it is employed without charges.

A social worker is not a permanent feature on the policlinic's staff, but can be employed, if need be. A rather rare occurrence, however, according to the doctor interviewed. Psychological support or counselling is not provided. Currently about 1000 patients are supplied with ART.

Though ART is offered according to protocol [guidelines], *second-line* therapy is *de facto* inexistent. Usually AZT+ 3TC plus EFV or NVP or LPV/r is prescribed as first-line therapy. If anaemia requires foregoing AZT, it can be replaced by d4T. In most cases of therapy failure, too, only one drug is replaced, i.e. if a patient does not tolerate the combination of AZT+3TC due to a AZT associated anaemia, AZT is replaced by d4T. Should the therapy fail in this combination (increase of CD4 cells or disease progression), only EFV, NVP or LPV/r is replaced.

The bacteriological laboratory of the policlinic is able to cultivate *Candida* cultures. All other fungi (*Aspergillus* spp., *Dermatophyten* spp. etc.) can neither be cultivated nor diagnosed here.

Are advanced diagnostic procedures (radiography, magnetic resonance imaging, computed tomography, sonography etc.) required, other clinics have to be used. Among different clinics (e.g. Oncology Clinic) co-operations have emerged so as to organize certain diagnostic exams in a more or less timely manner. It was impossible to find out, on which basis these co-operations work. But it is a fact that the exams have to be paid by the patient.

We had the opportunity to inspect the excellently equipped district hospital. By admission of the policlinic's physicians, it is almost impossible to get an appointment for HIV-infected patients there. Exorbitant high sums of money by Donetsk standards are demanded from the patients for the exams. The obligatory cost-free exams, the district hospital is obliged to conduct, are generally accompanied by very long waiting periods (MRI at least three months; likewise endoscopic examinations). Co-operation seems to be impossible here.

The Central HIV Laboratory

The policlinic's lab is another one of its core areas. Being a „specialized central lab“ only the following exams are performed here:

- All confirmatory tests, if an ELISA test is positive from clinics on neighbourhood and oblast level; plus samples from other areas (Mariopol, parts of Lugansk oblast).
- According to the lab director, currently approx. 400 HIV tests are performed per day. To confirm positive test results, three different kits are tried out. Additionally we were shown rapid tests, intended for emergency use and distribution (within the scope of post-exposure prophylaxis, PEP, births etc.).
- All CD4 cell counts per flow cytometry for Lugansk, Mariopohel (planned) and Donetsk City/Oblast. In answer to our questions the lab doctor told us that the cytometer was repair-prone. If a technician was required, as had been repeat-

edly the case, he had to travel from Kiev. In the meantime obviously no exams were possible.

- Central collecting of all blood samples that will be send to Kiev for VL determination.
- BB, clinical chemistry and hepatitis serology (Hep B and C) as well as CMV, EBV, Toxo, HSV IgM and IgG-antibodies.
- HIV ward (all lab exams that can be combined from the above).

Likewise the determination of antibodies with ELISA for Epstein Barr Virus (EBV), Cytomegalovirus (CMV), Herpes simplex Virus-1 and -2 (HSV 1/2) and Toxoplasmosis is exclusively performed at the central lab. A complete blood count with differential can be made.

Furthermore there is BTS for clinical chemistry, but only 12 parameter are admitted here by the city council's health board:

- Total protein
- Glucose
- Cholesterol
- Bilirubin
- Albumin
- Lactate
- Triglyceride
- Kreatinin
- Urea
- Alpha Amylase
- ALT
- AST

CRP is currently not determined (we only received evasive answers to our inquiry about the reason for that). Haematology exams, like the evaluation of bone marrow smears, are not performed in this lab. Only the district clinic has the possibilities for bone marrow smears and their processing. More specific exams (Parvovirus B19, MAI etc.), however, cannot be performed there either.

The policlinics established a separate transportation for blood samples, which collects the to-be examined samples from the regional policlinics, and brings them to the

central lab. Viral load tests cannot as yet be performed, but during our stay the acquisition of a thermal cycler for PCR was authorized by phone from Kiev. So far, a transporter with cooled blood samples travels once a week the 600 km on the night train to the laboratory in Kiev for viral load testing, the lab director told us. Likewise resistance determinants can only be performed in Kiev. Yet this exam had been a rather rare occurrence, she pointed out, not least to the fact that the patient had to pay for it himself.

Attached to the lab is a so-called bacteriological lab, where blood cultures can be processed. But apparently the self-produced culture media don't always provide adequate results. Also available is the cultivation of *Candida albicans*; all other fungi, however, cannot be diagnosed. The bacteriological lab doctor was not familiar with India Ink Stain for Cryptococcus. Neither did she know to determine cryptococcal antigen in screening. The lab director, however, was familiar with this procedure. Here seems to be a substantial flaw in the care system.

We witnessed the lab as a functional department that attached to the policlinics represents an important part of the policlinic structure. We could observe the processing of about 150 serum samples. But the lab's key function seems to be the performance of HIV testing – primary and confirmatory. The lack of bacteriological experienced lab personnel was apparent.

The HIV/AIDS Ward

House and Rooms:

Following the reconstruction of a building complex within the psychiatric health centre that took several months, the new HIV ward was inaugurated in spring 2007. The site is located at a distance of about 20 km from the city centre amidst fields. To get there one has to take the car or the bus, which goes once an hour. The bus stop is located at about 3 km from the ward.

By admission of Dr. Grazhdanov the HIV ward was renovated and built for a total of 1 million US dollars. The roof was refurbished and the building's outside revamped. Access to the building was equipped bed- and disabled-friendly with a ramp. The building's interior was gutted, safe for its supporting walls and the rooms fitted in later. Hence now almost every patient room possesses an en-suite bathroom, either equipped with shower or bathtub as well as with sink and a toilet. Most of the rooms are equipped for three beds, but can be augmented, if need be. The house consists of two floors with a capacity of about 60 beds. The basement is refurbished as storage and technical room respectively.

On the first floor are located besides the patient rooms a kitchen, a doctor's lounge and office as well as a storage room for medication. There is a niche for the nurses with a bell system from the separate rooms as well as a so-called manipulation room, which equals a procedure room. All instruments for blood taking blood samples, to apply butterfly needles and other examination purposes (spinal needles used in lumbar puncture) are stored here. According to the nurses the examination as well as the medication storage room are usually and only accessible for the patients in the company of a nurse.

Distribution of Rooms /Patient rooms:
The patients are organised according to disease aspects, thus the first floor (mezzanine) is designed for the severely ill, whereas the second floor caters to the less sick people. From the altogether 22 patient rooms on the lower floor, five were furnished as so-called isolation rooms with 15 beds. These rooms are equipped with an isolation sluice, but without separate access from the outside.

The second floor features almost the same room arrangement (save for the kitchen), but has no isolation rooms. Every room possesses generous separate bathrooms with either shower or bath.

According to Dr. Grazhdanov the international HIV/Aids Alliance made their support for the project »hospital ward« subject to the condition that at least five rooms were

set up for final palliative care. Right now, however, the ward does not meet the requirements for a palliative medical approach in the strict sense of the term – neither in medical, medication or care regard. So far there are neither analgesics containing opium available nor has a licence for their application been issued.

In the basement rooms is an additional water reservoir with six water containers, holding a volume of 2,000 cubic litres each; that is a total volume of 12,000 cubic litres. The ventilation system is installed in the basement, sucking in the outside air and providing the patient rooms with slightly cooled fresh air. Apart from the technical equipment a storage room for deceased patients is located here. In a separate room is a refrigeration system for max. one corpse as well as the possibility to store several corpses without refrigeration.

Admittance of Patients and Visitors:

Patients are admitted following medical guidelines. The patient enters the building via the regular entrance and has immediate access to a general examination room. A nurse will collect the patient data, followed by the initial medical exam. This includes: anamnesis, physical exam; if need be, taking of blood samples and suspected diagnosis. Before entering the ward the patient is supposed to clean him-/herself in a bathroom attached to the examination room. Afterwards the patient is allocated to a patient room.

It seems that visiting hours are handled quite freely. A visiting room was furnished for the get-together of patients with their relatives, which is located close to the exit. But obviously there seems to be the possibility to visit patients in their rooms. In the case of terminally ill patients friends or relatives have the option to adopt the care, which is rather similar to the [West-] European concept of rooming-in.

The Team:

The team consists of four infectiologists working in shifts of 24 hours each. There is only one doctor present per shift. Apart from the four physician positions there are 17.5 posts established for nurses, which are actually occupied by 12 persons. The

male and female nurses are not involved in the immediate care, but elaborate in co-operation with the doctor the medical-therapeutic and diagnostic plans, the latter draws up daily for each patient. They organise the taking of blood samples, prepare infusions, organise the patients' medication and are in charge of the ward's daily run. So-called »sanitarias«(paramedics) are employed for the more specific nursing activities involving the patient (like washing, feeding etc.); they are not certified care workers. Their tasks are, for instance, to assist the patients in their personal hygiene and their food supply etc. For that reason 22 posts were established, which are shared by 15 *sanitarias*. Social workers and psychologists are neither planned nor available.

Catering:

The canteen kitchen of the whole complex (psychiatry and AIDS station) organises the catering. The district's health board funds the kitchen.

Lab:

The policlinic's lab widely assumes the lab chemical examinations required in the AIDS ward. Available are:

- CD4 cell count
- Clinical chemistry, blood count
- Hepatitis serology for HBV and HCV (but without PCR)
- CMV, HSV, EBV and toxoplasmosis - serology

For the therapy of different diseases medication is available that, however, has to be purchased by the patients in most cases. The ART is provided charge-free.

Invasive and diagnostic operations:

Different invasive surgical procedures are performed in the ward. Apart from lumbar puncture to obtain cerebrospinal liquid, certain body cavities can be tapped, including the puncture of the pleural cavity to obtain trans- or exudates respectively, as well as the puncture of ascites (peritoneal cavity fluid). All invasive punctures are performed by doctors in the so-called manipulation-rooms. At present there is no sonography

equipment available to make the punctures secure by determining the amount of liquid and location of withdrawal.

Diagnostic equipment:
On the grounds there is a radiology equipment to take thorax and abdomen X-rays. By admission of the station/ward doctors, exams and their results are available within a day. There are no further diagnostic facilities on the clinic grounds. Each diagnostic exam (CT, MRT, sonography etc.) requires transportation services, for which the patient has to pay himself.

Consultants:
The AIDS ward is headed by infectiologists. To be examined by other experts like neurologists, Augenarzt/ophtomologists or surgeons the patient has to leave the ward and be transferred to the corresponding clinic, or alternatively the consultants are brought by car to the Aids ward; a procedure that requires a lot of time and resources.

Medical Care Structures for Tuberculosis Patients in Donetsk Oblast

Preliminary remark:

In 2004 the tuberculosis incidence in Donetsk Oblast was about 86.7 per 100,000 inhabitants (civil population), including the prison inmates raises the TB incidence to 96.1 per 100,000 (WHO report 2004). Thus it is notably higher than the national average. (Figure 2)

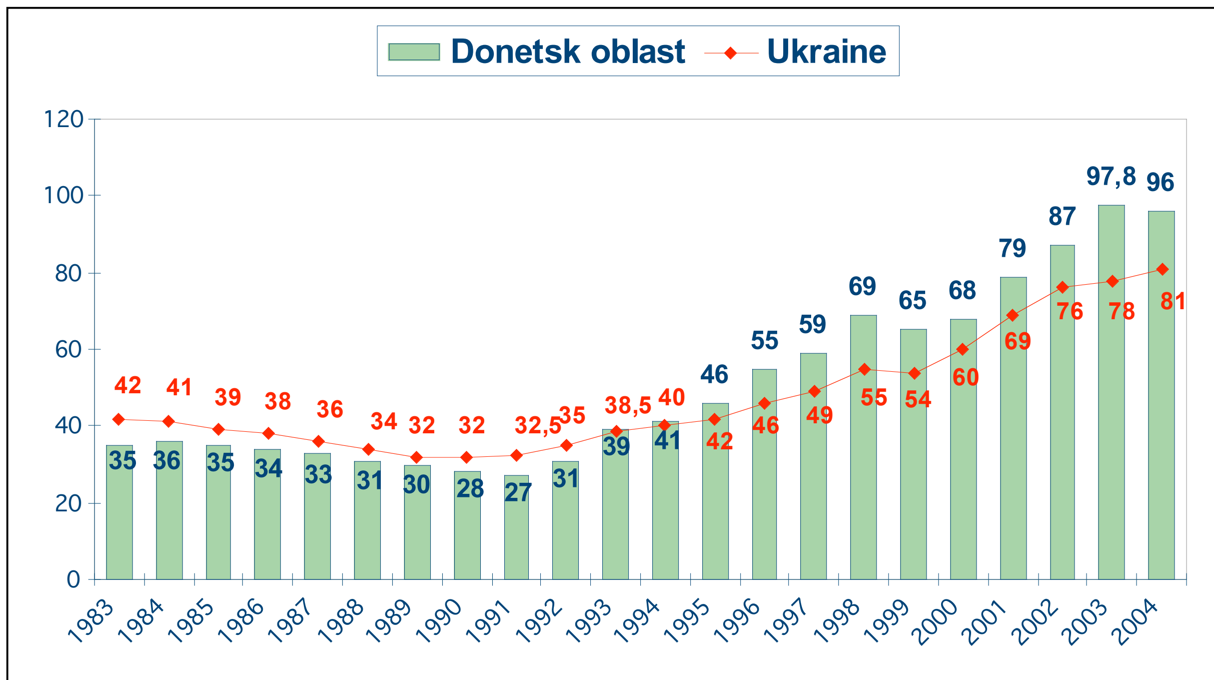
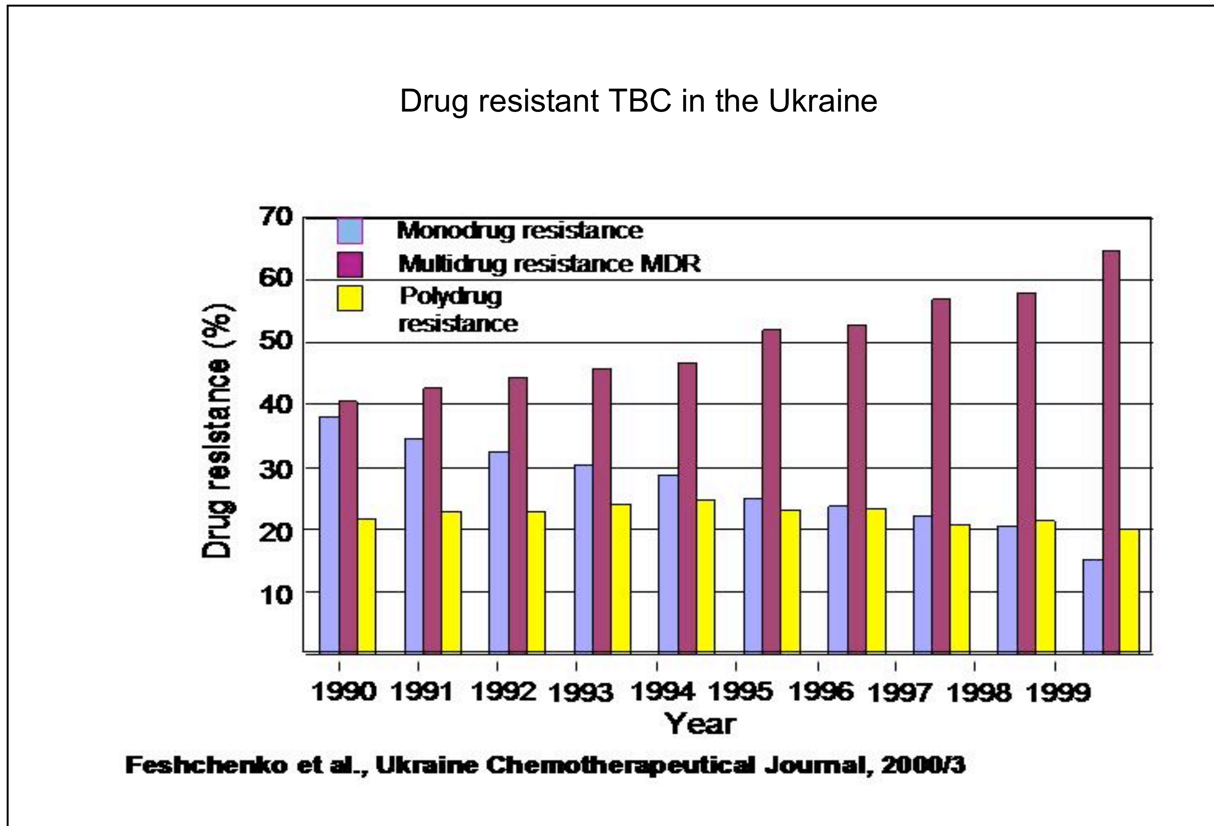


Fig. 2: TB incidence in Ukraine (1983-2004)

In Ukraine, tuberculosis is probably the most frequent opportunistic infection of people infected with HIV. Especially in Ukraine the percentage of multi-drug-resistant TB (MDR-TB) is the highest of all former SU countries. The treatment of MDR-TB is extremely complex and difficult, extremely resource absorbing, and it requires a degree of compliance and responsibility of the patient – just like the HIV treatment.

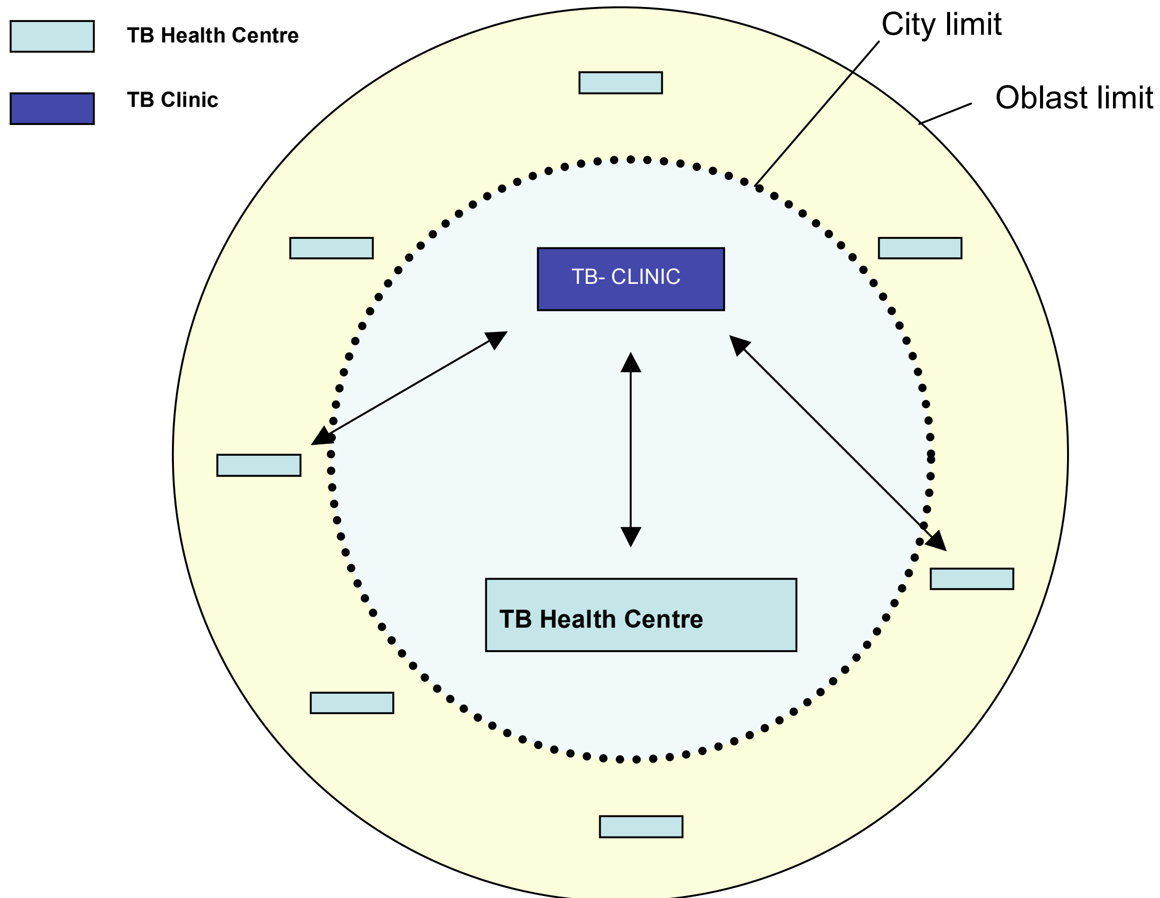


TB Health Centre, TB Clinic of Donetsk City and TB Health Centre of Donetsk Oblast:

For many years now there is a medical (administrative) structure for tuberculosis in Donetsk with two independent care modules, first off for the city of Donetsk, and then for the district of Donetsk.

There is a municipal health centre (dispenser/dispensaire) that is a general hospital for the long-term treatment of tuberculosis. This is where the care and treatment of patients infected with tuberculosis is organised. All patients suspected of tuberculosis have to present themselves there and only the tuberculosis expert is allowed to make the primary diagnosis. Afterwards patients are registered and allocated to regional health centres. The physician at the health centre decides upon the choice of drugs

for the quadruple therapy, as well as if the patient has to be hospitalized or can be treated as an outpatient.



Depending on the doctor's decision the patient remains at the health centre in question or starts a therapy as an outdoor patient with frequent checks at the health centre. The health centre is in charge of the regional structure, that is, each region is allocated to a health centre that applies for both, the city district as well as the province.

The second care branch is provided by the TB Clinic (also called district hospital). Here the cases of tuberculosis are treated that develop complications during therapy like relapse, the need of surgical interventions, MDR tuberculosis etc. The idea is that patients receive the necessary intervention at the TB clinic, and can return after

completion of treatment to the responsible regional health centre. Inside the TB clinic the patient can be attended by different specialists.

Yet when it comes down to it, this principle is hardly ever realised. No taking into consideration the disastrous room and hygiene conditions (e.g., no facilities to isolate patients, sickbays filled beyond capacity with care given by family members, without protection against contagious pulmonary TB etc.), the TB clinic is incapable of the performing the arising tasks. According to the clinic's surgical director this was due to several reasons. For one thing, he attributed it to the fact that the clinic's and health centre's staff of physicians was completely over-aged: more than 80 % of the doctors are over sixty and 32 % of the established positions vacant. By admission of the director, there is a dramatic need for junior physicians.

There is a quite high infection rate among the staff; protective measures are almost inexistent. The motivation of doctors and nursing staff to commit themselves is rather low, he explained, especially regarding the care of co-infected people (HIV and TB). Work overload, insecurity and fear of infection coupled with a lack of motivation had caused increasingly difficulties in the handling of co-infected persons, who without care and diagnosis are re-allocated to the policlinics.

Moreover, the director mentioned, a competitive situation had accrued, since unlike the TB physicians, the HIV-serving doctors received a »risk« allowance. Subsequently re-referral was internally often justified with the argument that »they should take care of their patients themselves.« A fatal situation for patients, since only pulmonlogists are licensed to prescribe TB medication. An interdisciplinary concept is almost doomed to fail in such a climate. The more so, as HIV-infected patients with drug abuse and TB co-infection are regarded as very disagreeable and difficult.

The tuberculosis medication is free, but here too, the accompanying therapies have to be paid by the patients.

Medical Substitution Maintenance Therapy for IDU

Preliminary remark:

The rate of new infections due to injection drug use (IDU) in Eastern Europe is many times higher than in Western European. Ukraine, the CIS and Estonia are only the tip of a gigantic iceberg. During the last five years in Ukraine alone 52.500 people have become infected by needle-sharing (source EuroHIV: mid-year report 2006, 2007, No.74). The HIV prevalence of drug users is over 40 per cent. All programmes issued to provide HIV-infected drug users with ART, depend on stabilising people medically and socially. Only then can the complex therapy be sustainable effective. This is currently unthinkable without substitution programmes. So far there are only individual attempts to establish methadone or other substitution therapies. Social realities caused to fail the attempt of introducing methadone as well as legal barriers. Popular notion maligns substitution therapy as giving out hard drugs at government expense. In 2005 a WHO funded media campaign was launched to increase social acceptance of the comparatively expensive buprenorphine (Subutrex°). Buprenorphine enjoys higher approval due to the fact that it is known as a painkiller, thus being considered rather a medication than a recreational drug.

Outpatient Substitution Therapy at the Regional Narcological Health Centre

In the fall 2005 the substitution programme started with 52 people (number determined by Ministry) following strict statutory requirements. One third of the persons are HIV infected, about 40% of the infected are treated with ART. Another eight to nine persons are prepared for ART treatment. The AIDS Centre of Donetsk City accompanies and takes care of the patients on a partnership basis.
Criteria to become included in this pilot programme are long-term drug use with several detox attempts as well as HIV status and the need for a antiretroviral treatment. The selection was made in cooperation with the AIDS Centre and the self-help group *Svitanok*. Since many people meet the above-mentioned criteria, a random choice was made. The only exclusion criteria are aggressive behaviour and longish ab-

sences. Urine controls for testing of illicit (drug) use are performed on an irregular basis, but have no effect on participating in the substitution therapy.

Psychological care is provided to a certain degree by the self-help group *Club Doors* (with professional psychologist). Their co-operation modus could not be specified. *Svitanok* also co-operates with the substitution programme and seems to provide above all social support.

In the long run the programme is scheduled for 90 patients, depending on the evaluation of the current participants. Next perhaps another 90 persons from another municipal health centre shall participate in the substitution programme, as well as in four more cities in Donetsk Oblast with 90 people each.

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Berlin, 30th of October 2007