



HIV/AIDS in Turkey Mission report.

- The mission was carried out by Michael GOETZ from the French NGO AIDES, from October 10th to 15th, 2005.
- Special thanks to Selim BADUR for supporting the organisation of this mission!



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• *Strengthening community-mobilisation on HIV and AIDS in Central and Eastern Europe*

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The objectives of these missions is to assess what works and what needs to be improved with regards to the responses to the HIV epidemic from the perspective of NGOs that are active in implementing HIV prevention, support, and advocacy at the grassroots level.

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1. Mission agenda and contact details of persons involved :

Monday, October 10th, 2005:

Prof. Selim Badur ("Head/ President") - **AIDS Savasim Dernegi** ("AIDS Prevention Society")
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Istanbul; info@aidswernegi.org.tr; www.aidswernegi.org.tr
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Sewal (project coordinator) – **IKGV - Human Resources Development Foundation**
Director: M. Muhtar Cokar, Association of activists
Zümrüt Cadessi, Istanbul

Duygu (general secretary, French-speaker), Garo, Sibel (volunteers) – **Positif Yasam** ("Positive life")
Young and only Turkish association of HIV-positive persons and their relatives/ close relations,
No premises (housed by IKGV), duygu_serthan@yahoo.com; garobabacan@yahoo.com;

Tuesday, October 11th, 2005:

Dr. Stephan Seebacher (Director), Mrs. Arzu Özsoy (Information officer) – **Turkish Regional Delegation- South Caucasus of Red Cross/Red Crescent Federation**
Cemal Nadir Sok n° 9, 06680 Ankara; ifrcr39@ifrc.org ; www.ifrc.org ; tel.: 00 90 312 44142 92; fax 00 90 312 441 38 66

Mr. Guner Umut (President) and 5 volunteers – **Kaos GL**
Gay and lesbian association
Gazi Mustapha Kemal Bulvari 29/12 Demirtepe- Ankara; dergi@kaosgl.com; www.kaosgl.com ; tel. /fax: 00 90 312 230 03 58;

Mrs. Serap Asar Brown (consultant) - **UNAIDS**
Focal point in Turkey, unique representative of UNAIDS in Turkey
UN House, Birlik Mahallesi 2, Cadde n°2, 06610 Cankaya Ankara, serap.brown@un.org.tr , tel.: 00 90 312 454 11 39, fax 00 90 312 496 14 61

Additionally, brief, informal, individual encounters/meetings:

Mrs. Karmen Bennett – **International Fund**, Mrs. Ayse Kayhan, psychologist, volunteer of the association **AIDS Savasim Dernegi**, Mr. Nejat Ünlü (president) of the association **Positif Yasam**

Wednesday, October 12th, 2005:

Mrs. Dr. Peyman Altan (coordinator STD-AIDS Mission, French-speaker) – **Ministry of Health**
Mithapassa Cadessi, Ankara; peymana05@yahoo.fr; peyman.altan@saglik.gov.tr
tel.: 00 90 312 435 69 37,

Prof. Dr. Serhat Ünal (Head of the Infectious Diseases Unit of Hacettepe University and "head/president"), Mrs. Aygen Tümer (coordinator) – **HATAM** (Hacettepe AIDS Treatment and Research centre)

"Association" of doctors and health professionals

Hacettepe Universitesi, Infectious Diseases Unit, 06100 Ankara,
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Saturday, October 15th, 2005:

Conversation with Prof. Selim Badur

Short observation of a training session designed for trainers, organised for the weekend by ASD, for doctors, dentists, psychologists (with, among others, Dr. Peyman Altan from the Ministry of Health)

Short observation of an "advocacy" workshop¹, organised for the weekend by UNAIDS for NGOs. Mainly attended by about 15 volunteers of **Pozitif Yasam** association.

Discussion with Serap Asar Brown (consultant) – **UNAIDS**

Mrs. Dr. Deniz Gökengin (general secretary) – **CYBH Savasim Dernegi**

(STD "Association"/society)

Hospital for Infectious Diseases, Aegean University, Izmir

deniz.gokengin@ege.edu.tr; tel.: direct 00 90 232 390 47 76;

Meeting/diner with several volunteers of **Pozitif Yasam**, among them the President of the association, Nejat Ünlü (English-speaker).

¹ There, I met a young lady doctor who happened to know Francis Knock and Latefa Imane of AIDES (back from the mid-90s when AIDES organized training sessions for Turkish NGO delegates...)

1. HIV Epidemiological situation :

According to the Ministry of Health, 1 922 persons are declared HIV-positive in Turkey.

350 to 400 of them are currently undergoing treatment, among them 220 are under Prof. Badur's care in Istanbul (whose unit also carries out all the virological and biological HIV tests in Turkey) and 150 under Prof. Ünal's care, in Ankara (whose HIV treatment and research centre, called Hatam, was the only AIDS centre of the country for a long time). The "actual" prevalence varies from 5 000/ 6 000 (according to Ministry) to 10 000 (according to some NGOs) or even 14 000 (according to UNAIDS). UNAIDS reckons there will be 50 000 HIV-positive cases by 2010.

The surveillance system used in the country is not flawless. Personal data (coded data) is not always comprehensive. According to Prof. Ünal, 40 % of declarations even fail to mention the gender of the person. The nature of contaminations would apparently be unknown in half of the cases, and heterosexual in the other half. The small remaining percentage accounts for homosexual intercourse (see also "unknown"?), IDU (injecting drug users), transfusion and mother-to-child transmission.

However, the epidemic remains mainly heterosexual. The classic profile of an HIV-positive Turkish person (according to Prof. Ünal) is a married man, having extramarital sexual relations (with prostitutes), or having spent several years working abroad (non abstinent). Turkish men generally refuse the use of condoms, and are ready to pay more money for unprotected sex. (See also "prostitution").

About 150 HIV-positive women are prostitutes from abroad (Moldavia, Rumania, Ukraine).

Most HIV-positive cases are concentrated in Istanbul and other big cities, mainly Ankara and Izmir, where access to information and to screening tests can be helping factors to finding out about one's HIV infection.

Mandatory HIV-HCV-HBV screening tests before every singlesurgical operation (imposed by a current ministerial decree) represent an absurd expenditure (amounting to millions of Euros!). The Ministry representative herself admits the absurdity of this measure, but comes up against hospitals and doctors' resistance, who consider that these tests give people a feeling of safety (see also "Refusal of treatment"!).

Apart from these ones, there is no mandatory screening test in Turkey (however a pre-marriage screening test can be suggested, arbitrarily, depending on the person). Tests are carried out anonymously but are not free (around 15 euros) in every hospital. It is also possible to get tests from private laboratories.

The Ministry of Health claims to have trained 131 doctors (general practitioners and specialists) to pre- and pro-test counselling, which approximately amounts to 1 doctor per city. ASD and HATAM associations of doctors are also starting to offer counselling trainings for doctors and nurses in Istanbul and Ankara hospitals.

Hepatitis epidemiological situation:

HCV: 1% of the population, by parenteral transmission, blood donation, 10% of IDU, sexual transmission.

70 % of chronic carriers

HBV: 4% of the population (!), transmission: mainly (50%) of unknown origins, or else by sexual transmission or "close family contact" (there are cases of entire families who are HBV+) and 1% of IDU

2. General health organization - Access to treatment :

70 to 80 % of the Turks (workers and their family) have health insurance scheme. Very little time ago, the 4 existing regimes (employees, workers, state employees and liberal professions) were merged together. The new insurance scheme undertakes to reimburse 100% of HIV-positive persons' antiretroviral (ARV) triple therapy (whereas it only undertakes 80 to 90 % of other treatment prices, such as antibiotics for example!).

The remaining 20 to 30 % of the people, namely persons with no income, are entitled to a "green card" that *theoretically* gives them the guarantee of a 100 % reimbursement of their medical expenses (see Issues below!).

Foreign nationals (people who do not have Turkish nationality) do not get any financial help or reimbursement for the treatments they may need.

In theory, every HIV-positive person who needs a treatment has access to an optimal therapy.

Three doctors have to sign a patient report, valid for 6 months, and then a prescription, valid for 2 months. Currently, only five ARV treatments are generally prescribed: Kaletra, Crixivan, Virmune, Videx and Zérit (in Combivir form). They all are available in hospitals and in town. In case of resistance, second-line treatments are imported individually for the concerned person.

In Turkey, **patients currently have to advance treatment expenditure**, which obviously is a problem for people with low income. The situation is even worse for second-line ARV treatments. Since they apply to few people, they are not yet integrated to the regular supplying network. They have to be imported, with long delivery times (more than a month). Moreover, the National Health Service usually only reimburse their cost after a 3-month period (cost of the treatment for a month > 1000 USD!).

Pozitif Yasam also draws attention to the difficulty for HIV-positive persons to support supplementary expenditure. Many expenses (nurse services and medical equipment for people who have to be cared for in their own homes, treatments used to alleviate ARV side-effects) are still borne by patients.

HIV-positive persons who hold a "green card" have to ask the representative of their local government for the reimbursement of their ARV medication expenses. For these reimbursements, local officials use the social solidarity budget allocated by the central government. The price of an annual ARV treatment (first-line triple therapy) approximately amounts to 10 000 USD, which corresponds to the price of a tonne of charcoal, the necessary amount for one family to spend the winter (Prof. Ünal admitted he had undergone pressure from local officials who had asked him not to renew prescriptions for "such a homo" because this was putting a strain on the local social policy budget). **Within this system, there is a real risk of treatment breakdown for HIV-positive persons, especially those living in rural areas!**

More generally, HIV-positive persons often face **treatment refusals** (dentists, other health professionals), and are invited to go to specialized units to be looked after. Volunteers of Pozitif Yasam all went through many and various refusals. Prof. Badur and Ünal confirmed the existence of this phenomenon. Prof. Ünal mentioned a recent refusal in the very university hospital of Ankara (in his own hospital!), where he had to insist strenuously so that a HIV-positive person (with undetectable Viral Load (VL) and normal T4 levels) could have a hernia operation.

The Ministry of Health representative herself recognizes the existence of these refusals and confirms that HIV-positive persons are almost systematically sent to units “specialized” in their treatments, i.e. mainly Istanbul and Ankara hospitals.

When they ask for the reimbursement of their medications, HIV-positive persons with social security scheme have to have their prescriptions (on which HIV+ is written in big letters) signed by their employer before sending them to their health insurance. **This procedure poses a serious problem of confidentiality!**

Prof. Badur and Ünal admit the absurdity of this situation. A volunteer of Pozitif Yasam testified that this was the reason why he had not started his ARV treatment yet. When this issue was mentioned during our discussion with her, the Ministry of Health representative brought up some reflection avenues to solve these problems: not mentioning “HIV” on prescriptions anymore, using “infection” instead of HIV, or using a code system. It will be worth keeping an eye on the evolution of the situation!

3. Access to generalist prevention:

Sexuality definitely being a taboo subject in Turkey (without even mentioning homosexuality, which is not prosecuted by the law, but is considered to be a sin), it remains difficult to publicly mention condoms, other than in a contraceptive context ("incitement to debauchery"). As for the way AIDS is perceived, the epidemic is still considered as a fatal disease that affects homosexuals (for men) and prostitutes (for women). Transmission modes remain largely unknown to all the classes of the population.

The State does not carry out any prevention campaign, and some ministers even put a brake on the projects that some NGOs try to set up. The Ministry of Education is absolutely opposed to the mere fact of telling pupils about the reduction of risks linked to drug use, which had been suggested by the Red Crescent. That NGO at least managed to negotiate the setting up of 1 hour of sex education per year in high schools.

According to the Ministry of Health, a law is being prepared to hand over health competence to municipalities. However, nothing leads to hope that this level of proximity will encourage cities to make stronger commitments in the field of prevention.

Public opinion remains largely influenced by the media, which all, without exception, convey negative pictures on AIDS and value the sensational over clear and objective information.

The national society of the Red Crescent is starting to lead public-awareness campaigns directed towards the young, in the form of a "milder" version of Red Cross/Red Crescent international federation campaign called "Pass on the truth about AIDS" (see below). The ASD association offers training to professionals (nurses, policemen, imams ²[!...]...) and also in high schools. Besides transmission modes, discrimination-stigmatisation is the main tackled theme. HATAM started programmes of public-awareness designed for professionals (doctors, dentists, teachers) and initiates prevention campaigns "through peers" with students and high school pupils.

The positive point to be observed is that the City of Istanbul gets committed every year, on December 1st, by putting billboards at the disposition of the ASD association and by giving them the right to occupy the public highway for a public march (which by the way gathers 500 to 600 persons every year) and for the setting up of public-awareness stands.

² According to Selim Badur, imams are not closed to the issue of HIV/AIDS; some of them suggest to tackle discrimination and even recommend the use of condoms.

4. Access to prevention - Vulnerable populations:

Prostitution:

No law officially bans prostitution in Turkey. There are brothels in every city. In Istanbul, 500 to 600 women prostitute themselves (source IKGV). They receive close medical follow-up and the access to condoms is guaranteed *in theory*, but in no way controlled (source Ministry).

HATAM carried out a study on the clients of a brothel in Ankara, which confirmed that men almost exclusively preferred not using condoms. The study also mentions a realist rate of 35 to 40 % of unprotected sexual intercourse (for references, get in touch with Mrs. Aygen Tümer, Hatam coordinator).

Street prostitution is a fast-growing phenomenon, especially since the recent arrival of women from Moldavia, Ukraine and Russia (and of their "pimps"³). Only in Istanbul (20 millions of inhabitants), there are about **40 000 prostitutes** (source IKGV). Most of the prostitutes, Turkish and foreigners, remain highly vulnerable to HIV. Their knowledge about aids is poor, even sometimes nonexistent, and they have a trouble imposing the use of condoms on their clients, who in the great majority violently refuse it or offer to pay more for unprotected sex.

Street prostitution is starting to be criminalized through the selective enforcement of a law about decent clothes. The police organize roundups, during which dozens of women are arrested. After paying a 600 USD-fine, they are dragged to the only public hospital (that accepts this population) in order to be subjected to medical checkups, which include HIV and HBV/HCV screening tests

These mandatory treatments can turn out to be counter-productive, according to the coordinator of the prevention project directed towards prostitutes. The "IKGV" NGO leads prevention campaigns in the streets, through distributing condoms to prostitutes and by encouraging them to take care of their health. Volunteers come up against the refusal of prostitutes to consult this hospital because of the traumatizing experience of police roundups and "mandatory treatments".

Transgender persons: According to Sewal, the lady coordinating the prevention project directed towards prostitutes at IKGV, being herself transgender and an ex-prostitute, a community mobilisation took place in 1996-1998 in Istanbul. Some transgender activists led information campaigns (on virus transmission, use of condoms, social rights, etc.) towards their peers. This initiative created a wave of solidarity and mutual aid, which was so strong that it could even include the "eviction" of a roommate (often from a squat) if she refused the health principle of the group. Condoms were then almost systematically used (transgender prostitutes can impose it to their clients more easily).

Today, almost nothing is left of this community campaign, transgender people having turned back to "consumerist individualism". IKGV and ASD are now starting to set up a new project of street prevention towards prostitutes, especially transgender ones. The two associations got a budget from the European Union to do so.

Again, according to Sewal, most Turkish prostitutes are not injecting drug users (IDU).

Injecting drug use (IDU):

According to several sources (NGOs and the Ministry of Health), injecting drug use is steadily increasing. Nothing is done to reduce risks associated with injecting drugs. The very concept of risk

³ A true story (source IKGV): A moldavian woman was recently taken by her pimp to the hospital of Istanbul. She had gone through Moldavia, Rumania, and Bulgaria and had been forced to sleep with around 40 men per day, for weeks (without condom). When she arrived, her infection had reached AIDS stage, she had tuberculosis, was HBV and HCV-positive, add syphilis, etc. She died the day after she was admitted.

reduction is not even understood by the main organized forces, except for NGOs. The Ministry of Health representative seems to believe in the principles of Risk Reduction, especially after having heard the convincing speech of a Croatian NGO, during the symposium held on October 10th and 11th, 2005, which was organised by UNAIDS (see below). However, she remains very sceptical (and so do NGOs) regarding her powers of persuasion within ministries.

For example, in Taksim, a district of Istanbul that concentrates many places for party, prostitution and drug trafficking, all the chemists refuse to sell syringes after 5 PM!

The regional office of the Red Cross/Red Crescent international federation would be ready to encourage local committees of the Red Crescent to start setting up syringe exchange programs, in case the government should give its go-ahead... which is far from being done for the time being!

There are two treatment centres for drug addicts (drug withdrawal programs) called AMATEM, in Ankara and in Istanbul.

There is no access to syringes and to condoms within the country jails.

Men having sexual intercourse with other men:

Even if no law prohibits homosexuality, its strong condemnation by society is a heavy burden for homosexuals (i.e. an expression used at Kaos GL: "*punished by society, not by the law*"). Discriminations and abuses are omnipresent, fed by taboos and traditions. Judges would more easily base themselves on their personal beliefs (fundamentalists), just as they do with the Kurds and non-Muslims. Up to two years ago, the government protected homosexuals against police abuses and tolerated the (discreet) presence of the association Kaos GL (founded in 1991).

Nowadays, this very government does not apply the same policy anymore. In 2004, Kaos GL tried to set up officially as an association (it was then an informal group, without legal recognition). Since then, the government has been trying to stop them, suspended their registration and almost intimidated the group in order to disband it.

Current negotiations on Turkey's European Union gave help to Kaos GL, by forcing the government to recognize it as an association. Kaos GL president wrote to the Prime minister. Until then, the government had never answered directly to questions, on the pretext that these matters were being debated⁴.

The association also underlined that a book of sex education, used by state education mentioned that one way to protect oneself from AIDS was to avoid homosexual sexual intercourse.

Homosexuals also suffer discriminations in the field of medical treatment access. They are not systematically rejected from hospitals or medical units but, depending on the place, or even sometimes on the day, they face delays, are sent to other units, etc. Wealthy homosexuals chose to go to private clinics to get treatments, and pay a heavy price (including for ARV treatments – see above "prescription reimbursement problems", "obligation to have prescriptions signed by employers"!).

According to Turkish education and tradition, men have to be powerful and virile. Heterosexual men can easily have sex with other men. In this case, they are exclusively "active" and do not consider themselves as homosexual (and neither do people around them). Just like for prostitution, these "real men" refuse to use condoms.

⁴Right before my departure, we got the good news that the government had apparently given up legal proceedings against Kaos GL. For the time being, the association is not threatened anymore!

Another interesting fact is that in Turkey, transsexuals quite easily get all the necessary legal documents for their identity change (pink identity card for women, blue one for men!).

5. State's policies and civil society:

The yearly budget allocated by the State to the management of sexual infections (including HIV and hepatitis) amounts to 80 millions USD. It includes the salary of hospital units nursing staff, medication reimbursements and screening tests. As an example, more than 1.5 millions of Elisa tests are used every year (about 1.2 millions during blood donations, the others being essentially mandatory preoperative tests).

Few condoms, financed by the State's budget, are distributed, only through family planning centres that offer specific consultations (about 100 health centres among the 5 000 that exist in the country). According to the Ministry of Health, family planning centres would be willing to commit a lot more in fighting AIDS. Of course, we will have to keep a watchful eye on the situation to see if these centres will be able to provide a prevention and medical care service that actually manages to reach vulnerable populations.

AIDS National Commission

The commission was created years ago, and is made up of representatives from the Ministries of Health, Justice, Education, Tourism, and National Radio-Television, from three AIDS management and prevention centres (ASD doctors "associations" (Istanbul), HATAM (Ankara) and CYBH Savasin Dernegi (Izmir)) and from the Red Crescent.

Everything is centralized in Ankara. Meetings at the Ministry of Health, which used to be held every year, have been held monthly for 4 years now (arrival of Red Crescent), but are often organised at the last minute, according to officials' availability.

Red Crescent, ASD, Hatam and CYBH associations are the only representatives of civil society. ASD, Hatam and CYBH got to access to the commission since they are mainly made up of professionals and presided over by professors of medicine. However, even for these associations, it remains difficult to make the State understand and accept their ideas and projects (what would that government say if it had to deal with AIDES or Act-up then! ...)

NGOs:

There are only very few associations dealing with human rights, humanitarian action and community health, in Turkey. Very few organizations work in the field of the fight against AIDS.

Red Crescent/Red Cross

The Turkey-South-Caucasus regional delegation coordinates the actions of national Red Crescent / Red Cross societies, by acting as an intermediary between them and the International Federation. In 2001, this national federation declared AIDS second priority after natural catastrophes for the Red Cross/Red Crescent movement. The regional delegation also adapted the international campaign "the truth about AIDS, pass it on" and supports national societies and local committees in their actions. This organization is very open-minded on sexuality matters, including on homosexuality and prostitution, and is also convinced of the validity of risk reduction actions.

Its director has the feeling that through its generalist and humanitarian approach, the Red Crescent organization could be the most accepted proximity player in the field of HIV/AIDS prevention.

Red Crescent Turkey

Various generalist prevention actions are already led out in the field (particularly directed towards young pupils). According to the lady representing the Ministry of Health, they would also prepare a project called "holidays for persons with HIV". The organization's headquarters are located in Ankara. (No representative met).

ASD = AIDS Savasim Dernegi ("AIDS Prevention Society")

Founded in 1992 by Prof. Selim Badur and fellow doctors, this association started its activities within the hospital premises, and then shared several premises with other associations in town. Recently, they eventually got their own premises. They share the infrastructure (secretary, meeting room) with an association of psychologists (who work in collaboration with them on the prevention project directed towards prostitutes).

The association does not get any public fund from the Turkish government, and mainly lives thanks to private funds that are most often collected during visibility/prevention actions directed towards the general public: December 1st, concerts, marches, other events (student festivals). Up to two years ago, three state workers (doctors, nurses) were on temporary assignment to the association, and were in charge of welcoming, listening and counselling people. Recently, two permanent employees (1 young woman studying psychology and an anthropologist) were recruited within the framework of two projects set up by ASD and financed by the European Union: prevention for prostitutes (along with the association of psychologists and IKGV) and a project designed to train professionals (mainly nursing staff).

Nowadays, e-mail and phone questions (check out their really nice Website) are handled by these two new employees and very often redirected to Selim Badur or another volunteer. There are 600 members-sympathizers in the association but very few activist volunteers. Now the association is trying to mobilize new volunteers, particularly among medical students.

Apart from this, the association organizes an open congress on AIDS every year (the Ministry of Health only attended one congress in 13 years), sets up training actions (families, high schools students, policemen, etc.), and poster campaigns for the general public, and organized several events around December 1st, among other a march that gathered 5 000 to 6 000 persons in one of the main pedestrian shopping streets of Istanbul (see pictures).

HATAM ("Association"/centre that fights against AIDS)

This centre is located within the university hospital of Ankara (next to emergency department), in the infectious diseases unit, run by Prof. Serhat Ünal. It is designed for HIV-positive persons, and also for persons who have questions about AIDS (sexual health, pre-test and post-test counselling, treatments, support to observance).

HATAM is an association of doctors, nurses, and social workers, founded by Prof. Ünal in 1997. Dr. Aygen Tümer started being its coordinator 3 years ago, when the association was officially recognized, after volunteers spent many years convincing the hospital administration. Of course, the fact that it is located within the hospital is ideal since HIV-positive persons and people with questions on AIDS do not go their easily.

The association publishes brochures and a medical letter, and offers trainings for professionals (about treatments, virus transmission). It started "peer-teaching" projects directed towards the young.

Prof. Ünal is very proud of it (since its actions are effective!) although also a little sad because he *loves teaching young people*.

He also has a project to open 4 other global management centres like HATAM in 4 other cities of the country.

AIMD, "Association"/society that fights against AIDS in Izmir (3rd city of the country). Presided over by Mrs. Prof. Dr. Okuyan. Its main activities are led by Mrs. Okuyan, who is retired. Some of the people we talked to criticize her for having a biased point of view about homosexuality. This NGO is invited to the national commission. (No representative met during our mission).

CYBH Savasin Dernegi, "Association"/society that fights against STDs, located in the hospital for infectious diseases of Izmir University. The general secretary of the association is a young lady doctor, Dr. Deniz Gökengin, who is highly motivated by the cause but does not have clear ideas on which projects should be led in priority or how to set them up (just like other NGOs). Short meeting with representative in Istanbul.

IKGV – Human Resources Development Foundation (HRDF)

This NGO leads several projects in the field of human rights and humanitarian relief, among them a prevention action directed towards sex workers (mainly transgender persons). The only person we met is Sewal, the lady coordinator of this project, who was recruited on the ground of her knowledge and skills of the field, having been herself part of the transgender prostitution circle.

According to Nejat, the president of Pozitif Yasam, this association develops many projects, but ("as very often in Turkey") works without a method and is incapable of giving clear results of its actions (to be checked, however, with its director maybe).

Pozitif Yasam ("Positive life")

For several years, some HIV-positive persons of Istanbul had been getting together in a regular yet informal way. In 2003, they set up a chat forum on the internet (hivpozitif@yahoo.com). During the summer of 2005, 15 persons created an association for the fight against AIDS. Three months later, there were already 50 members (HIV-positive persons, volunteers, and family, mainly communicating through a mailing-list). About 20 persons (among them 2 or 3 HIV-negative people) now get together during weekly work-group sessions.

HIV-positive persons had to choose an HIV-negative president to represent them. All the HIV-positive members fear violent reactions of condemnation and discrimination, so much so that they do not dare publicly speaking about their association to find new members or volunteers, to make a name for the association, to concern the press or other partners than doctors.

Volunteers highlighted the importance of the serious lack of family ties. In Turkey, the relationship with the mother is generally very strong and not being able to share one's sufferings with her and with the rest of the family is very harsh. HIV-positive women (who are many in the association) also have to face the issue of children custody (or infected husband).

Their first project is to find premises of their own (for the time being, they get together in IKGV premises, at home, or in a bar), in order to be able to welcome people. They want to be able to formalize auto-support (group talks), set up prevention actions for HIV-positive persons, and then, later, to set up prevention and information actions outside their association (in priority towards homosexuals).

Volunteers also mention a great need for information and counselling about their treatments, they feel doctors (even specialists) do not listen enough to them and even do not support them enough. There is also a feeling of disappointment, yet without any aggressiveness, towards the society fight against AIDS. Volunteers waited for some help or support from ASD for three years, in vain. It was only recently that they mutually understood that ASD mainly sets up generalist prevention and visibility actions, and that the field of community mobilization was yet to be occupied – by par Pozitif Yasam!

An "AIDS house", which would gather management (from therapeutic apartments to palliative care, the actual form has not been well decided yet), treatment counselling, specialized services, etc. is one of their numerous projects (or wishes) in the medium term.

The association was invited for the first time to the "official" meeting on October 10th and 11th, 2005, along with representatives of Ministries and specialist doctors. This dialogue and presentation of the World Fund meeting was organized by UNAIDS (see below).

This meeting strengthened president Nejat Ünlü's desire to "shake up" the habits of government representatives, to know the real figures of the epidemic, to understand its management and to bear the claims of HIV-positive persons.

A genuine committed activist!

Kaos GL

About 15 homosexuals created an informal group in 1991. They regularly meet up during group talks, publish a very comprehensive fortnightly review, which often includes articles about HIV/AIDS, and also created their own website. Their premises are located right in the centre of Ankara, on the fifth floor of a spacious and welcoming building.

As an association, Kaos GL is tolerated by Ankara and by the government, as long as it remains discreet (See difficulties faced at the moment). The situation of the association reflects the condemnation climate that prevails in the country and prevents people from openly living their homosexuality

The association wants more homosexuals from Ankara to know about Kaos GL, but does not exactly know how to do so in the climate that pervades Turkey. Its members are thinking about how they could set up HIV/AIDS prevention actions towards men (no priority main line, even if members of the association are very interested by the issue).

Lambda

Gay and lesbian association, Istanbul. They have very few contacts with Kaos GL d'Ankara, and, according to some of the people we met, do not want gay people and HIV/AIDS to be lumped together. They do not want to work with ASD. No representative met.

The Global Fund – UNAIDS

The Global Fund allocated 4 million dollars to Turkey, for prevention projects, essentially directed towards most vulnerable populations (HIV-positive persons, prostitutes, IDU, men having sexual intercourse with other men). The Global Fund joined forces with UNAIDS to make government members aware of the fact that the sine qua non of this fund releasing was the implication of the civil society, firstly and especially of the country's community health associations. In principle, 50% of these funds should be allocated to NGOs.

The GF and UNAIDS set up a meeting, which was held on October 10th and 11th, 2005, and was designed for organizations involved in the fight against AIDS (the national commission, and also Turkish NGOs!). NGOs from Moldavia, Macedonia (working on Harm Reduction with IDUs) and Croatia (Men having sex with other men) were invited to this work session. Representatives of NGOs from abroad proved to the government members and to doctors (who were quite stunned by their presentations!) that community health actions can have effective results (the Global Fund and UNAIDS were indeed justifiably very pleased with what they achieved!).

UNAIDS' strategy to strengthen the abilities of Turkish NGOs is the following: a few weeks ago, and for the first time, Mrs. Serap Asar Brown, consultant of Focal point Turkey and only representative of

UNAIDS, gathered NGOs (almost only volunteers of Pozitif Yasim in the group!) and invited the "Ukrainian Network for people living with HIV and AIDS"⁵.

During the weekend of October 15th and 16th, UNAIDS organized a second meeting, in the form of an "advocacy workshop". A journalist was invited and the central theme approached during the session was to know the media better and use them better to fight AIDS (by refusing manipulation), as well as to build up actions around December 1st.

UNAIDS also offers to support NGOs in their analysis, strategy setting up, and project creation ability. A 3-month follow-up period is expected to be set up until the end of 2005, to support report writing, website creations, etc.

Moreover, UNAIDS is willing to better identify education and prevention needs in Turkey. In order to avoid the traditional embarrassment linked to talking about sex, Mrs. Serap Brown thinks about using the internet or an interactive CD.

UNAIDS and the Global Funds insisted so much on the fact that NGOs were the ones supposed to handle projects that the Ministry of Health representative expressed doubts (during a private conversation) on the 4 million USD being fully used, because of the lack of organizations able to lead practical actions out in the field.

⁵ According to this lady, the association does a great job!

6. Conclusions:

Discrimination – Condemnation:

Most of the media still convey the idea that HIV = gays (for men) or prostitute (for women), thus bringing about a persistent condemnation by the general population, who has little access to information on the topic of HIV/AIDS. HIV infection remains synonymous with death and transmission modes are still not widely known. HIV-positive persons have to conceal the truth and live a hidden life. They also suffer from the widespread condemnation climate maintained by the whole Turkish society.

The health organization of Turkey gives rise to discriminations concerning treatment access (example of prescriptions signed by employer, and of medication reimbursement for people depending on local social funds, not specifically designed for health matters).

Other HIV-positive persons receive proper HIV treatments, but the reimbursement of extra expenses (side effects, opportunistic diseases, “comfort” medication, people who have to be cared for in their own homes) is not borne by social security.

Ever-growing commitment of the civil society:

The emergence and tenacity of at least two associations (Pozitif Yasam and Kaos GL) is a sign of hope. Turkey's European Union membership process already played a positive role in favour of gay people, even if the government only officially recognized under duress.

The same positive duress is now being used by the Global Funds and UNAIDS, which are organizing events (colloquiums and workshops) to convince authorities to recognize the role of associations and the principle of community health

The Ministry of Health representative and other high-ranking officials who took part in the colloquium that UNAIDS organized on October 10th and 11th, 2005, are now aware of the fact that the budget allocated by the Global Funds for the setting up of HIV/AIDS prevention and support actions is necessarily and strictly linked to the commitment of vulnerable communities...Will the government become aware of this fact too? These representatives of the State also claimed they were aware of the fact that these very communities are not organized enough (in structured associations) and that there no field organization is able to lead prevention actions directed towards priority populations... for the time being

The Ministry of Health representative said she was ready to learn about other countries' experience (particularly about SEP, syringe exchange programs) and seems interested about working in collaboration with AIDES at the European level.

The most important thing will be to follow up the evolution of Pozitif Yasam, of its projects, and of its recognition by the Ministry of Health (participation in national commissions!) as well as the perseverance of the Global Funds in its mission to force the government to involve the civil society, and especially concerned persons, in the management if this issue.

Pozitif Yasam volunteers are highly motivated but need to provide their association with a real structure, to learn and share experiences (maybe with partners of the INTEGRATION projects? Maybe with AIDES?)...In short, they probably need some methodological support in associative democracy and NGO project management.

Other pertinent NGOs we regrettably could not meet :

- **Red Crescent Turkey** in Ankara (already led several AIDS public awareness actions, might get involved in harm reduction for drug users).
- **IKGV**, director Muhtar Cokar. To go deeper in the content of other actions led by this association. See if it could set up community health actions (street prevention, SEP)...
- **CYBH Savasin Dernegi**, "association"/society that fights against STDs, located in the hospital for infectious diseases of Izmir University. The general secretary is a young lady doctor, Dr. Deniz Gökengin. She is willing to lead actions, but does not really know how to do so (methodology and financing).
- **AMATEM**, two treatment centres for drug addicts (drug withdrawal programs), one in Istanbul, and the other one in Ankara. To get in touch with them: contact Selim Badur.
- **Lambda**, Gay/Lesbian Association, Istanbul. However, they may not really want to talk about AIDS, as they mention their discontent about the widespread idea that gay = AIDS. They do not really work in collaboration with Kaos GL of Ankara or with ASD of Istanbul. A former member of the association, who left, accepted to take over the presidency of Pozitif Yasam association.

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