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

# **Report on the HIV/AIDS Situation in Lithuania**

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## Executive Summary:

Serious questions remains regarding the exact scope of HIV/AIDS in Lithuania: the official published number of cases of HIV suggest that Lithuania has somehow been far less affected that nearby Latvia or the Kaliningrad Region. Yet, the fact that many cases of HIV are diagnosed in patients who are already in the advanced stage of AIDS, the fear of know one's HIV diagnosis (which seemingly prevents many Lithuanians from undergoing testing) and the 299 cases of HIV found in 2002 in a single prison all suggest that the HIV problem is far greater than the Lithuanian authorities are ready to acknowledge.

If early action was taken when the Lithuanian Governmental AIDS Center was set up in 1989, its pertinence today is highly questioned by NGOs, local activists and some medical practitioners. First and foremost, it remains extremely difficult for People Living with HIV in Lithuania to have access to adequate treatment and care : less than 30 persons have access to antiretroviral (ARV) treatments – while up to 180 people need ARVs now – and that number is expected to increase greatly in the short term and will include a growing proportion of intravenous drug users. People living with HIV/AIDS find it also very difficult to have access to health care overall – which demonstrate that medical practitioners in Lithuania need to urgently learn how to provide adequate care to people Living with HIV, including best practices for prescribing ARV to drug users. Free and anonymous HIV testing need to become much easier to access.

The variety and creativity of local NGOs that are active on HIV/AIDS embody the strong commitment of many Lithuanians to fight HIV/AIDS and defend the rights of People Living with HIV and AIDS and of members of vulnerable communities: the Lithuanian Government could vastly strengthen the Lithuanian responses to HIV by developing direct dialogue with their local NGOs and by funding directly specific prevention and support project to be implemented by community-based organisations.

## **I. HIV/AIDS in Lithuania**

### **1. Numbers**

Official data from the Lithuanian AIDS Centre as of January 7, 2004, indicates there are 845 HIV cases registered in Lithuania, of which 762 are men. Lithuania's biggest cities are the most affected – Klaipėda (203) and Vilnius (145), and also Alytus, which had a major HIV outbreak in 2002 in its penitentiary (299). [2]

A lot of HIV cases are diagnosed in the late stage of AIDS, which means the real number of HIV cases is much greater than registered. [2]

### **2. Routes of Transmission**

The main route of HIV/AIDS transmission in Lithuania, as in many countries of Eastern Europe, is through intravenous drug use (678), accounting for about 80% of all cases, while 8% are infected through heterosexual intercourse. [2]

However, according to UNAIDS, another significant route of transmission is among men who have sex with men: "... hidden epidemics are possibly occurring among men who have sex with men..." [4]

### **3. Access to ART**

In Lithuania only 27 HIV positive persons receive highly effective antiretroviral treatment (ART) although the number of persons in need is between 80-180. [5] None of them is or was an injecting drug user. Drug users are initially denied ART because of the popular theory they won't be able to adhere to strict ART regimens. According to Lithuanian law, ART can be prescribed only for those who have already developed AIDS, pregnant women and those who have had contact with an infected person for sure. [2]

### **4. HIV Development**

The first HIV case was registered in 1988, but registered AIDS and death cases show that HIV was already circulating in 1985 in Lithuania's biggest cities: Vilnius, Klaipėda and Kaunas.

The growing consumption of drugs, increasing tourism, trade and other social and economic factors provided favourable conditions for HIV to spread. [3] The first wave in the rise of HIV was observed in 1994. Initially, HIV reached the seaport Klaipėda first, where sex work and drug use prospered. In 1994, the first HIV outbreak was detected there when six port sailors were tested HIV positive. [3] In 1995 ten HIV positive sailors were already registered. Most of the sailors acquired HIV during the end of the 1980s and the beginning of the 1990s. [2] Since 1995, Klaipėda has had the biggest number of registered new infections every year. In 2002 for instance, there were 397 HIV cases diagnosed.

Up until 1997 the main HIV transmission route in Lithuania was through sexual intercourse. The second wave in the rise of the HIV epidemic is attributed to 1997 when HIV transmission through injecting drug use accelerated. The first person to acquire HIV infection through drug injecting was diagnosed in 1994. In 1996 already half of diagnosed HIV cases were due to injecting drug use. In 1997 about 90% of all HIV cases were attributed to this mode of transmission.

Since 2000 a new trend in HIV epidemiology has been observed – the epidemic is being diagnosed in smaller Lithuanian cities.

The average age of HIV positive drug users in Lithuania is 30 years. The tendency is that HIV is diagnosed for younger under-aged persons, who start abusing narcotic substances and do not have knowledge about the harm related to drug abuse or information about "safe" drug use.

In 2002 the first case of an HIV positive woman was registered. [2]

## 5. National Programmes on HIV/AIDS

The systematic regulation of HIV/AIDS prevention policy in Lithuania began in the early 1990s, after the Lithuanian AIDS Centre was opened in 1989 and the government passed the first *AIDS Prevention and Control Programme* in 1990. Up till now, six programmes of its kind have been adopted. The main objective of the programmes is prevention amongst vulnerable populations. However, the comparatively low prevalence of HIV in the country has led to low priority being given to HIV/AIDS prevention at the level of the national health care policy agenda. However, as a result of public relations campaigns and education work, the *HIV/AIDS Prevention and Control Programme* was included as a priority measure for public health care insurance by Lithuanian Parliamentary decree in July 1998.

On October 1, 2003, the Lithuanian Government approved the *National HIV/AIDS Prevention and Control Programme for 2003-2008*. The new programme sets two priorities, including improving treatment and reducing discrimination against people living with HIV/AIDS as well as prevention amongst vulnerable populations. The programme calls for prevention through the following priority action patterns:

- prevention of parental HIV transmission,
- prevention of sexual transmission of HIV,
- prevention of mother-to-child transmission,
- improvement of health and social care of people living with HIV/AIDS, and improvement in access to care and treatment,
- improvement in HIV/AIDS diagnosis,
- co-ordination and supervision of HIV prevention and control programmes implemented at regional and local levels.

The programme calls for more than 120 prevention measures to be implemented in 2003–2008. The long-term goals are to prevent the further spread of HIV/AIDS, to stabilise the epidemic and to reduce HIV related harm to society. Therefore, by pointing out that the increasing number of HIV infections may significantly increase the demand for state funds required for treatment, early HIV prevention remains one of the programme's main priorities. According to the government plan, the Ministry of Health will control implementation of the programme and Lithuania's AIDS Centre will handle its execution. [3]

### **3 questions to Prof. Alvydas Laiskonis, head of service on infectious diseases.**

#### **Why do you think is Lithuania, officially, much less affected by the HIV epidemic than nearby Latvia or the Kaliningrad Region ?**

Lithuania is surrounded by countries with a very high HIV epidemic. According to official figures, Lithuania has indeed been much less affected. But we do not have in Lithuania any anonymous and free HIV testing where anyone could just walk in to get a test. Free testing is possible if you're considered to be a member of a "risk group". I think (with many other specialist in infectious diseases) that the HIV epidemic in Lithuania is mostly "underground". Testing services is very centralized (only one AIDS center in Vilnius) and we do not have a network across the country. The study that revealed the huge HIV epidemic in the Alytus Prison demonstrates that our HIV epidemic is far greater than the official data.

#### **What would you say are the most urgent needs for People living with HIV/AIDS (PLWHA) in Lithuania ?**

The priorities for PLWHA in Lithuania are:

To receive optimal and up-to-date antiretroviral (ARV) combination treatments

Adequate medical monitoring and follow-up for patients, by specialists in infectious diseases (today, all treatments are prescribed only by one doctor who is a gastro-enterologist).

Testing of emerging viral resistances to ARV – as there may be resistant types of HIV now developing.

To provide adequate monitoring and treatment for the undesired effects of ARVs

To prevent HIV in Prisons (including access to testing, to care, and specific support for PLWHA who are about to go out of prison).

#### **What needs to happen in order for these needs to be met ?**

As rapidly as possible, we need to decentralize access to HIV testing and HIV/AIDS care and treatment in Lithuania. We need to organize a network for free and anonymous testing centers, starting in the 5 biggest cities in Lithuania. Another idea, the core priorities of the National AIDS Center (monitoring, prevention and information, etc) need to be separated from the work for specialist in infectious diseases (testing, treatments, follow-up of patients).

Overall, we ought to learn from the best practices now in place in several western European countries to

implement them in Lithuania. We need to put an end to the detrimental individual quarrels fueled by personal ambitions, and we ought to learn to work together.  
(March 2004)

Prof Laiskonis published two books about HIV in Lithuania and has worked since 1993 in partnership with the Tourcoing Hospital in France.

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## II. Vulnerable Populations

### 1. Injecting Drug Users

Drug users make up 80% of all HIV cases in Lithuania; moreover, this group is alienated and difficult to reach due to problems created by their HIV status and the discriminatory attitude expressed by the public. People in this group face numerous problems related to inaccessible and inadequate medical treatment and social care. People with addictive disorders and positive HIV status experience double discrimination (due to drug abuse and HIV) and intolerance from the public. Laws that could stipulate the provision of adequate medical and social services to people with addictive disorders and HIV infection are non-existent. Furthermore, many drug users lack basic knowledge of effective HIV prevention measures and those services provided by medical institutions and social care. [3]

In 1995 Lithuania started implementing harm reduction programmes. The Ministry of Health approved the launch of experimental methadone substitution treatment (ST) programmes in Vilnius, Klaipeda and Kaunas (also Druskininkai in 1998). Currently, methadone substitution treatment programmes are carried out in five Lithuanian towns. In 1997 syringe/needle exchange programmes were introduced. The volume of healthcare services provided is increasing every year, and more drug users are reached; there is growing awareness of the availability of medical aid; individuals diagnosed with drug dependence cannot be subject to criminal/administrative charges for drug use and confidential treatment facilities are available. In 2001, three additional centres for addictive disorders were opened in 3 cities. In order to provide more comprehensive care for drug users, the primary link of the healthcare system is also utilised: from 1996, the decentralisation of ST programmes to primary healthcare centres was initiated and is being successfully implemented up to the present. [3]

#### **An assesment of the situation for Drug Users with HIV :**

The AIDS Centre gives priority to preventive and rehabilitation work among drug users. It is, however, a deplorable fact that its whole work is limited to an attractive web page, a perfectly equipped five-room office with a conference hall and reception parlour. The Centre also has three buildings within the green zone at Nugaletoju Street with offices where the work with drug addicts is carried out, whereas there is no room for the sick and infected, and there is not a single hospital bed for AIDS patients/HIV positive persons in the whole of Lithuania, nonetheless, the statistics about the infected is gathered on a regular basis to beg for money from the state budget. Speaking frankly about the current situation, it should be mentioned that the conditions in which the medical personnel is working with the infected drug users are more than catastrophic. A small room of no more than 12 square metres with a single never-to-be-opened window, where the used syringes are exchanged for new ones, and where purulent wounds are treated, whereas the medical personnel has to inhale all these odours because of absence of any ventilation. The situation has reached the moment where the personnel of the consulting-room has to buy medications, bandages, etc. at their own expense (...).

Article released in 2004 by V.O. Pozityvus gyvenimas (The Positive Living NGO)

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## **2. Sex Workers**

According to the Lithuanian AIDS Centre, there were approximately 1800 - 3000 sex workers (SWs) in Vilnius in mid-2003.

A survey of sex workers carried out in 1998 and 2001 by "Demetra" – Social Diseases Consultation Centre - showed that the majority of SWs working on the streets of Vilnius are between 21 and 25 years old. Normally, the younger age group is comprised of non-Vilnius residents from all over the country who usually haven't graduated from high school - sex work being the only way for them to earn money for a living. The share of drug users among sex workers in 2002 was 65%.

There is an increasing trend towards drug use amongst new SWs - these women were usually already using drugs before starting sex work and for many, providing a sex service is the only way to earn money for living and drugs. Injecting drug use is common among street sex workers. There are three known HIV cases among sex workers in Vilnius at this time.

Provision of sex services is prohibited by Lithuanian law. [3]

However, the prevalence of HIV does not exceed 5% in any of the subpopulations of Lithuanian residents; therefore, according to WHO classifications, Lithuania remains a low prevalence country. [1]

## **III. NGOs Working in the HIV/AIDS Field**

NGO activism in the HIV/AIDS field in Lithuania is still relatively low, though there are a couple organisations working with vulnerable populations and people living with HIV/AIDS.

### **1. Initiative of Drug Users Mutual Support**

#### *1.1. Brief History*

Based on the initiative of the Vilnius Centre for Addictive Disorders (VCAD), a club for methadone programme participants was established. In the club, patients spent free time together sharing their experiences and so on. With the support of the Vilnius Centre and the NGO "Relief" (Salpa), the club was given office space for the establishment of a mutual support group. In September 2001, eight of its members formed the non-governmental organisation "Initiative of Drug Users Mutual Support" (IDUMS). These people are still working in the organisation. A board of five members was elected and is presided over by a chairman.

#### *1.2. Activities*

The following are the main areas of IDUMS activities:

- 1) One of the areas is the representation of rights and legitimate interests of drug users (of both organisation members and non-members). Members of the organisation participate in the work of the substitution treatment (ST) medical consulting commission at the Vilnius Centre for Addictive Disorders. In order to improve the ST programme and to better reflect the needs of its patients, IDUMS suggested several changes to the rules of the ST programme, which were taken into account.
- 2) As the majority of drug users are not aware of their rights, IDUMS pays considerable attention to their education and informs them about applicable laws and legal regulations. With support from Open Society Fund – Lithuania, research was carried out in order to find out whether drug users know their rights, which rights are violated more frequently and which violations have the greatest influence on their status in society.
- 3) Members of the organisation also represent drug users in court and act as public attorneys. There have already been 7 trials of this kind and all of them had favourable outcomes (there were no cases of imprisonment).
- 4) IDUMS members consult drug users and their relatives on available treatment methods and options.
- 5) Analysis of legal regulations in Lithuania demonstrated existing collisions and discrepancies between laws as far as the rights of the given social group were concerned. In many countries of the European Union,

drug abuse is not prosecuted and certain minimal amounts of drugs are allowed for possession without fear of being arrested.

In Lithuania, however, any contact with drugs is regarded as a violation of the law, although this conflicts with provisions of the *Law on Narcologic Care*, which claims that drug abuse is a disease and the resulting use of drugs is a manifestation of this disease. The organisation seeks to acknowledge *de facto* dependence on drugs as a disease. For this purpose, IDUMS representatives participate in public discussions on drug abuse and HIV in the media and take part in seminars and conferences held both in Lithuania and abroad.

- 6) In order to protect the rights of people with addictive disorders, IDUMS members take part in meetings held at the Ministry of Health and the municipality of Vilnius. Furthermore, IDUMS circulates open letters to government authorities expressing its opinion on issues related to addictive disorders.
- 7) Active co-operation with the media is maintained. Articles on the organisation and its activities and opinions have appeared in the national press.
- 8) Negative public opinion experienced by drug users is felt in the communities of other towns where the majority of drug users fear asking for assistance from specialised treatment institutions. Therefore, the establishment of similar groups in other Lithuanian towns is essential. The organisation has established contacts with former drug users in Kaunas, Klaipeda, Alytus and Mazeikiai.
- 9) As the members of the organisation are former drug users, they often lack the skills and competences required for running a non-governmental organisation. Thus, IDUMS also focuses on capacity building in the organisation.

### 1.3. Co-operation

- Vilnius Centre for Addictive Disorders is the organisation's principal partner;
- Klaipeda Centre for Addictive Disorders;
- Lithuanian Association of Addiction Psychiatry;
- Lithuanian Positive Group;
- NGO "Relief";
- NFPO "Committee for Protection of Human Rights to Medicine";
- Central and Eastern European Harm Reduction Network, which supports the organisation's activities (IDUMS is a member of the network);
- Communication with similar NGOs in Russia, Ukraine, Moldova, Georgia, Bulgaria and the Netherlands.

### 1.4. Funding

Main funding is received from the Open Society Fund – Lithuania, the Open Society Institute and the Baltic-American Partnership Programme. Office space is provided by Vilnius Centre of Addictive Disorders and the NGO "Relief".

### 1.5. Lessons Learned and Future Challenges

IDUMS is the first organisation of its kind in Lithuania involved in the protection and representation of the human rights of people with addictive disorders. IDUMS contributes to the transformation of public opinion. In so doing, it bases its activities on experience and the promotion of research-supported solutions to drug users' problems. In less than two years the organisation not only managed to attract the public's attention, but also received attention from government authorities. Thanks to the initiative of the organisation, similar groups of people are becoming involved in similar activities in other cities of the country.

The work inside the organisation is managed according to the principle "help others and you will help yourself". The organisation's activities help members to organise their time and to integrate into society and its activities. Further improvement of the working skills of organisation members is planned and the preparation of consultants who could assist in the establishment of mutual support groups in other cities is also intended.

The organisation will continue advocacy for people with addictive disorders, promote amendments to Lithuanian legislation on drugs and ensure the accessibility of medical and other services to most vulnerable groups, including the availability of timely antiretroviral therapy, adequate assistance to people living with HIV/AIDS and other diverse services to drug users. [3]



## **2. Association of Women Affected by HIV/AIDS and Their Relatives**

The Association of Women Affected by HIV/AIDS and Their Relatives was created in 2000. The goal of the association is to help HIV/AIDS infected women and women of groups involved in risky behaviour to solve the social, legal, medical and psychological problems they encounter.

The association spreads information about the transmission routes of HIV/AIDS, fights against the isolation, discrimination and stigma of sex workers, represents their rights and distributes information about help available for HIV infected women and their family members.

The members of the association operate on a voluntary basis. Every day about 5-10 people approach the organisation for help and information. The association also collaborates with non-governmental organisations from Eastern and Western Europe.

Goals and objectives:

- create background for helping HIV infected women and women involved in risky behaviour to fight against isolation and discrimination;
- disseminate the experience of HIV positive women and stimulate the creation of self-help groups and their co-operation, get in contact with other organisations working with HIV infected women and women from groups involved in risky behaviour;
- spread information about HIV prevention;
- disseminate information about sex workers' HIV infection and HIV mother-to-child transmission prevention strategies;
- disseminate information seeking to familiarise society with the problems HIV positive women encounter, fight against their isolation and discrimination and represent their rights;
- provide social, legal, psychological and medical help for HIV positive women and their family members. [6]

## **3. Lithuanian Positive Group**

Lithuanian Positive Group was founded in 1993, so last year it celebrated its tenth anniversary. The group unites people infected and affected by HIV/AIDS, their relatives and volunteers. It was founded when the number of HIV cases in Lithuania overstepped 10, and three of those infected realised that no one could solve their problems better than they could. To this date Lithuanian Positive Group has 15 people living with HIV/AIDS and 10 volunteers actively working for it.

The group's main goals are to unite people infected and affected by HIV/AIDS and seek mutual support for PLWHA and their relatives.

In achieving its goals Lithuanian Positive Group tries to provide people affected by HIV/AIDS with the material, social and moral support to facilitate their adaptation to society, maintain contacts with other community organisations in Lithuania as well as abroad, participate in international projects, represent the interests of HIV affected people in governmental institutions and maintain contacts with the media.

Over the last two years the group has been actively involved in advocacy, the ultimate goal of which is to decrease the stigma of HIV. This should be based on closer relationships with society, ensuring respect for human rights and stressing the right to relevant, adequate and accessible health care services for all HIV affected persons in need.

In 2003 Lithuanian Positive Group started a one-year programme called "We live". The purpose of this programme is to maintain closer links with society, especially youth, and to decrease the detachment of HIV/AIDS affected persons. The programme consists of different projects devoted to the dissemination of the right to information about HIV/AIDS, solving problems encountered by affected people and the formation of HIV/AIDS politics in Lithuania as an equitable member of the European community.

Sponsors: Open Society Institute, North Countries Information Bureau, GlaxoSmithKline Office in Lithuania. [5]

### **3 questions to Igor AFANASJEV, Chairman of the Lithuania Positive Group**

**Why do you think is Lithuania, officially, much less affected by the HIV epidemic than nearby Latvia or the Kaliningrad Region ?**

It a big question – maybe it's not the case – Lithuania is a very catholic country and people are afraid to do test to know their status – HIV tests are available but there is a lot of fear – I think they are afraid to know their status.

**What would you say are the most urgent needs for People living with HIV/AIDS (PLWHA) in Lithuania ?**

We would like to change the laws and practices about medical treatments – Today, only people with AIDS

have access to treatment – but people living with HIV should have much earlier access to adequate treatments and care instead of waiting until the symptoms become very severe. This is our priority at the Lithuanian Positive Group. Less than 30 people are getting antiretroviral treatments today.

**What needs to happen in order for these needs to be met ?**

Health professionals in Lithuania need to learn how to provide good medical care and support to People living with HIV. We need specialized services with staff highly qualified on HIV– which is really not the case at this point. Such specialized centers exist in Latvia for instance, but not in Lithuania. Also, access to healthcare is extremely difficult for PLWHA, even when it's not related to HIV (for dental care for instance). To get medical care, one must go to your local poly-clinic and you must tell your HIV status. If I were to have medical problems myself, I have no idea of where to go and who would accept to take care of me. If I ever needed to have an operation, that would be extremely difficult.

(March 2004)

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#### **4. Coalition of Vulnerable Groups**

On February 2, 2004, the constituent assembly of the Coalition of Vulnerable Groups will take place. The coalition won't have an official status - it will be an informal organisation uniting both non-governmental and governmental organisations.

The main goals of the coalition will be:

- assist government to form rational policy on drugs and other dependence causing substances also on HIV/AIDS;
- develop society's tolerance for vulnerable groups in Lithuania.

#### **IV. Thoughts on Joining the European Union**

*Association of Women Affected by HIV/AIDS and Their Relatives*

Svetlana KULSIS, Director: "I assume that the situation concerning human trafficking and illegal migrants will change. Lithuania even now is known as the country of cheap sex and problems will deepen as the demand for sex services will increase". [6]

*Initiative of Drug Users Mutual Support*

Kestutis BUTKUS, Director: "The good thing is that HIV/AIDS is a bigger priority in the agenda of national governments of European Union countries than in Lithuania. Thus Lithuania should make efforts to reach the same level. The threat is that a lot of funders will become unavailable". [7]

#### **V. An international perspective: Country visits by Finnish HIV/AIDS NGO experts.**

Jari KESÄNIEMI and Bengt LINDBLOM carried out on behalf of the Finnish AIDS Council 2 missions to Lithuania, as part of the Integration Project.

Lithuania was visited twice during the project while Lithuanian colleagues visited Finland once. Our Lithuanian colleagues familiarised themselves with different organisations providing services for HIV positive people in Finland, both in Helsinki and in Turku. Furthermore, during the project we also made excursions to the Lithuanian Positive Group, the Lithuanian Aids Centre, a Lithuanian clinic for infectious diseases, a local needle exchange point and the Finnish Embassy in Vilnius. We also contacted a member of the Environmental and Health Department of Public Health in Lithuania, Dr. Neringa MALECKIENE.

As describe above, two main reasons for getting an HIV infection in Lithuania have been the use of intravenous drugs and having unprotected sexual intercourse. The worst HIV (and drug-related) problem is inside Lithuanian prisons, where the work of the employees of the Lithuanian AIDS Centre mainly takes place. One distinctive feature about Lithuania is that it happens to be a Catholic country. Naturally, the values and the behaviour of citizens are being affected by their religion. While in Lithuania, we also sensed a certain type of racism and rejection towards the local Russian minority.

Dangerous decisions by the Lithuanian AIDS Center:

The first trip to Lithuania took place in summer 2002. During that trip we heard about an unbelievable decision made by the Lithuanian Government to stop ARV (antiretroviral) medication for those in need. The director of the Lithuanian AIDS Centre, Dr. Saulius CHAPLINSKAS, was behind this decision. He summarised the Lithuanian AIDS problem with two words, "money" and "attitude". We could not help wondering about the opinions and attitude of the director of the Lithuanian AIDS Centre himself....

This same problem was discussed in a magazine called Aids 2002 -Today (Aids 2002 - Today, Thursday July 11, page 5), which was being distributed at the Aids Conference in Barcelona. However, the situation changed again in summer 2003. The Lithuanian Government now has enough money for HIV medication for at least two more years – but then again, the number of people who are in fact getting treatment remains extremely low.

Who pays for healthcare ?

One of the biggest problems in Lithuania, as well as in other Baltic countries, is that people are not automatically covered by any kind of health insurance programme. In Lithuania for example, being covered by the local health insurance programme depends on whether one works or not. This means that there are quite a few people who fall outside the realm of all support systems in Lithuania.

The commitment of People Living with HIV/AIDS

Out of all the voluntary organisations in Lithuania, we only met the Lithuanian Positive Group and its leader Igor AFANASJEV. The group has no facilities of its own at the moment, but can use the facilities of the state-run AIDS organisation "whenever those are available". Considering the group's minimal resources, we could only wonder about the active role of its leader Mr. Afanasjev, both in the social and international sectors. It was quite amazing to follow the work of a human being who fights against his own illness and gets no support from his country while at the same time working hard for a better future for all Lithuanian HIV positive people.

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## Bibliography

1. Sveikata - monthly periodical. – May 2003;
2. Lithuanian AIDS Centre – [www.aids.lt](http://www.aids.lt) – 2004/01/07;
3. HIV Prevention amongst Injecting Drug Users in Lithuania: Best Practices/Central and Eastern European Harm Reduction Network – 2003;
4. UNAIDS AIDS Epidemic Update: December 2003;
5. Lithuanian Positive Group;
6. Association of Women Affected by HIV/AIDS and Their Relatives
7. Initiative of Drug Users Mutual Support

## APPENDIX A - An open letter from the Lithuanian Positive Group to Lithuanian Seimas and Government

By the Chairman of the Lithuanian Positive Group  
[Originally released in 2002 in Lithuanian]

The mass media is fully preoccupied with an outbreak of HIV infection among the prisoners of Alytus jail today (2002). There are more than 200 HIV positive prisoners detected in Alytus prison. One should consider the fact that many of them have regular sexual relations with their wives. Many have been released from prison and nobody knows how many are in an incubation period. Consequently, these numbers are not accurate.

Could it have been avoided? Already for 13 years there have been numerous HIV prevention programmes in Lithuania. Every year the state spends 10 million Lt. (2 700 000 USD) on the prevention of drug addiction. Everybody started talking about the outbreak of HIV in prisons, not only Mr. Adamkus, the president of Lithuania, but common people as well.

The impression is that only today everybody faces the problem of AIDS in Lithuania, and prisoners in jail have sex and take drugs. If every officer of the state handling the problem of AIDS would honestly work and spend the money the state appoints from the budget on these matters relevantly, then the epidemic in Lithuania could be prevented. At the same time nobody has uttered a word about access to treatments and care for HIV positive people. What is waiting for these HIV infected people? I am actually one of them. What does the future hold for those who have already been in Alytus prison and to whom prophylaxis are not going to help?

It would be interesting to know why those 361 people who work and pay taxes regularly, bring up children or take care of their parents are excluded from medical care. Why are they left on their own and can only hope that God will help them? There are 576 registered cases of HIV but only 6 persons are being treated. **The Ministry of Health assigned no money for HIV/AIDS medications.** Only with the help of doctors from the Lithuanian Aids Centre and friends from abroad can we continue our treatment. But the future is unpredictable. Until 2001 the Ministry of Health was appointing only 65 000 Lt. (18 000 USD) on medicine to treat HIV positive people. This money is enough for 2 - 3 patients.

This year the money has not been assigned yet and the requests we sent to the Ministry of Health were left unanswered until May. Maybe there is no answer? Or are they sitting and waiting for a second epidemic, counting those who are dead because of AIDS?

Who will treat us and when, or will they treat us at all? This question is open and it tortures many HIV positive people who need to be treated, their parents, their children, their relatives, their friends and their doctors.

It is more logical to prevent the epidemic, am I right? Maybe we have acquired the habit of taking the issue seriously only after the disaster has already happened?

Nowadays there exist many new antiretroviral medicines, which not only slow the progression of the disease and make the life of the person longer, but also give them the possibility to live a normal life, go back to work and take care of their children. Lethal AIDS cases have decreased greatly in all developed states of the world, which is an advantage for everybody in society. The advantage of treatment is obvious because HIV positive people live much longer, pay taxes and continue to be a non-divided part of society with all responsibilities and guarantees.

I appeal to Seimas of Lithuania and Government to find the possibility to get treatment for people with HIV/AIDS, which we will reward with hard work and by taking an active role in preventing an HIV epidemic in society.

I hope that medicine capable of eradicating HIV completely will soon be found and will help many millions of people to live.

Chairman of Lithuanian Positive Group, HIV positive for 11 years