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# UNOPA

The National Union of the Organizations of Persons Affected by HIV/AIDS

**We are** the only nongovernmental federation in Romania made of NGOs of persons affected by HIV/AIDS focused on advocacy for promoting and defending the rights of the people infected and affected by HIV/AIDS.

Since June 2000 until present time, UNOPA defended and promoted the rights of thousands of children, youngsters and adults infected with HIV or affected by AIDS, as well as the rights of their families:

- ⌘ Access to continuous, free of charge and nondiscriminatory ARV treatment
- ⌘ Equal access to services and medical care
- ⌘ The right to social protection adequate for the needs of the people infected/affected by HIV/AIDS and to adapted psycho-social support
- ⌘ The right to nondiscrimination and social inclusion
- ⌘ The right to education and socio-professional integration

**We are** A NATIONAL-LEVEL VOICE FOR:

- ⌘ People infected with HIV or affected by AIDS (children, youth, adults) in Romania
- ⌘ The families affected by HIV/AIDS in Romania
- ⌘ Community level NGOs (23 members in present) from Bucharest and from 15 counties in Romania, which are accounting for over 1200 beneficiaries, persons infected with HIV or affected by AIDS.

**We are** A NATIONAL-LEVEL VOICE THROUGH:

- ⌘ The activity of Promoter and Vice-president in the National Commission for Monitoring, Controlling and Preventing HIV Infection Cases.
- ⌘ Organizing conferences, seminars and work meetings
- ⌘ Organizing/participating in public campaigns, protests, open letters, solidarity appeals, manifesto, press releases or conferences
- ⌘ Organizing exhibitions and shows
- ⌘ Publications (monitoring reports, "*Pozitiv*" magazine)
- ⌘ Court representation
- ⌘ Advocacy/Lobby for:
  - Promoting and respecting the rights of people living with HIV/AIDS
  - Influencing public policies in Romania for meeting the needs of people living with HIV/AIDS
  - High-quality public, medical and social services



## OTHER ACTIVITIES

- ✘ Support for the institutional development of UNOPA member associations:
  - Training
  - Support for infrastructure/equipment
  - Support for evaluating and satisfying the needs for organizational development and for creating/strengthening social services
- ✘ Strengthening the NGOs network of persons infected/affected by HIV/AIDS
- ✘ Participating in common actions
- ✘ Provides the medium for network info exchange by a Central Secretariat
- ✘ Moral and/or financial support for the setting up of community associations, by persons living with HIV/AIDS
- ✘ Material support (food, drugs, clothing)
- ✘ Facilitating juridical assistance

## INTERVENTION STRATEGIES

- ✘ Research and analysis (monitoring, juridical instruments, public policies)
- ✘ Training
- ✘ Advocacy and lobby
- ✘ Information, education, communication (IEC)
- ✘ Strategic partnerships
- ✘ Networking

## INTERVENTION PRINCIPLES

- ✘ Rights (universal and specific) – instruments for reducing the physical and social HIV vulnerability of persons, reducing the impact and the transmission of the HIV virus
- ✘ Support for HIV infected children, youth and adult leadership at all the levels of answer to HIV/AIDS
- ✘ Support for the institutional development of the member NGOs
- ✘ Support for the development of the social services offered by the UNOPA member associations.

## UNOPA MEMBER NGOs

- ✘ The Association „Noi și ceilalți” - Bucharest
- ✘ The Association „O rază de lumină” - Mangalia
- ✘ The Association „Benone” - Tîrgu-Mureș
- ✘ The Association „O șansă pentru viitor”- Pașcani
- ✘ The Association „Licurici” – Giurgiu
- ✘ The Association „Zâmbete de copii” – Galați
- ✘ The Association „Lizuca ” – Bacău
- ✘ The Association „Glasul inimii” – Iași
- ✘ The Association „Angel’s Hope” – Suceava
- ✘ The Association “Neghiniță”- Tîrgoviște
- ✘ The Association “Viață și Speranță” – Giurgiu
- ✘ The Association “Protecția” – Mizil
- ✘ The Association „Alexiana” - Piatra Neamț
- ✘ The Association „Pro Sănătatea 2000”- Constanța
- ✘ The Association „Tereza” – Botoșani
- ✘ The Association „Speranța Băniei” - Craiova
- ✘ The Association „Inocență și speranță” - Reșița
- ✘ The Association „Iris” - Vaslui
- ✘ The Association „Speranța Copiilor 2000” - Bârlad
- ✘ The Association „Îngerii păzitori” – Medgidia
- ✘ The Foundation „Andreea” – Mediaș
- ✘ The Association “Fundița Roșie” - Piatra Neamț
- ✘ The Association “Pro Karma” – Tîrgu-Mureș

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## INTRODUCTION

Since April 2001 up to present, **The National Union of the Organizations of Persons Affected by HIV / AIDS (UNOPA)** has developed, with financial and technical support of **the UNICEF Office in Romania**, and later in 2003, of the **Romanian Family Health Initiative (ISFR) – Partnership coordinated and financed by the Research and Training Institute (JSI) and financed by the Government of The United States of America, through the United States Agency for International Development (USAID)**, a monitoring system for the cases of violation of the rights of persons living with HIV/AIDS.

In 2004, the monitoring activity is developed in the UNOPA project “**The initiative for promoting and efficiently defending the rights of persons living with HIV/AIDS**” financed by **The Global Fund to Fight HIV/AIDS, Tuberculosis and Malaria**.

By this monitoring system, that includes collection, centralization and systematic and standardized analysis of the info regarding rights violation of persons infected and affected by HIV/AIDS, **UNOPA** desires: **efficient promotion and respecting the persons infected and affected with HIV/AIDS rights in Romania, changes at the legislation and social policies level in the field and the improvement of the medical and psycho-social assistance services for persons infected and affected with HIV/AIDS**.

The data presented in this report are the result of the monitoring analysis performed by the UNOPA monitors team<sup>1</sup> between **April - June 2004**, based on a standard methodology. The collection of data instruments has been established based on national legislative references from the HIV/AIDS and disability field. The monitoring process

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<sup>1</sup> The monitors team has been made by 19 principal monitors and 11 secundar monitors, persons infected and affected with HIV/AIDS, from UNOPA's member NGOs.



focused on 2 areas – **health treatment/services** and **special social protection** – and had as target population, the beneficiary of UNOPA's member associations, persons infected and affected by HIV/AIDS, from Bucharest and 14 counties: Călărași, Giurgiu, Constanța, Iași, Galați, Botoșani, Bacău, Caraș-Severin, Mureș, Sibiu, Dolj, Neamț, Suceava, Vaslui.

In some cases, the interviewed persons have documented their rights violation and in other cases, rights violation of other persons, HIV positive children in their care.

From the total of **1356 interviews**, we have documented **789 rights violation cases**. From this, **50.5% refers to right violation in the field of treatment and medical care, 30.5% are violations in the field of special protection of children infected with HIV/AIDS, 3% from the field of adults special protection, 3% from the field of the family affected by HIV/AIDS and 13% from the field of the rights of the person's with disabilities personal assistant.**

Keeping in mind that this monitoring report is not a scientific research with national relevance, the number of documented cases is less important, the accent falling on the nature of the violations and the way these violations are affecting the quality of the life of persons living with HIV/AIDS.



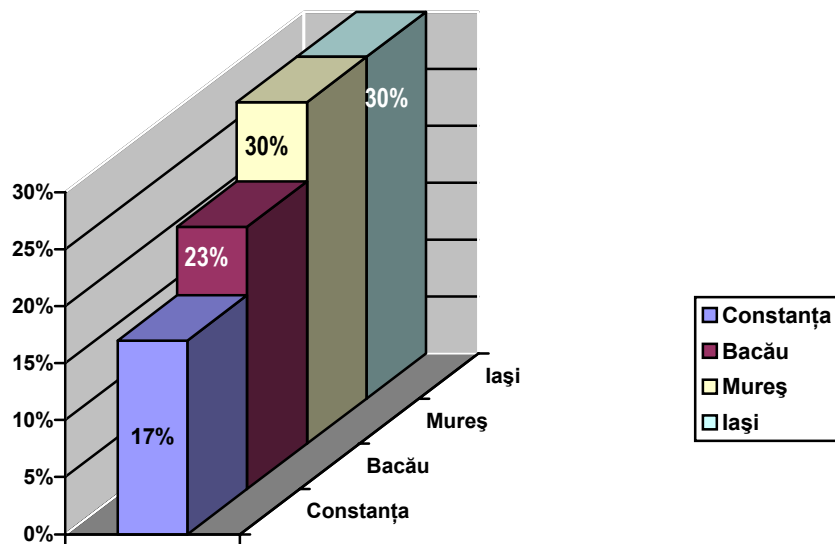
## 1. TREATMENT AND MEDICAL CARE

In the field of “Treatment and medical care” we have documented **399 rights violation cases from which:**

- ✘ 33% related to not performing viral load tests, according to the National Therapeutic Guide (in Bucharest and in Constanța, Bacău, Botoșani and Vaslui counties).
- ✘ 26% related to not performing the CD4 analysis, according to the National Therapeutic Guide (in Bucharest and in Constanța, Bacău, Botoșani and Vaslui counties).
- ✘ 26% related to drugstores’ refusal to accept free / compensatory prescriptions (ordered by the documented violations: Botoșani, Bucharest, Suceava, Vaslui and Mureș counties). The unreleased drugs that affected the budget of the family with sums exceeding 2 million lei/month: antibiotics, liver-protective, vitamins, antifungus.
- ✘ 10% related to discontinuity of the antiretroviral treatment due to disfunctions in hospitals supplying/distribution management of antiretroviral drugs (in Constanța, Bacău, Iași, Mureș and Sbiu counties).
- ✘ 2% related to the denied access to dental care (Bacău and Suceava counties).
- ✘ 3% related to incomplete medical records, which led to the impossibility of presenting the patient’s medical file to the expertise committee in order to establish the disability degree; related to the food that does not justify, from a qualitative and quantitative point of view, the sums spent by hospitals for the daily meals for HIV positive patients; related to the absence of rest rooms in the infectious diseases sections in some hospitals, a great risk situation for persons infected/affected with HIV/AIDS to contract other infections, as well as delays in the antiretroviral drugs distributions with up to 8 hours/day, during which the patients had to wait in the hospitals without getting any kind of medical care (in Constanța, Caraș-Severin counties and Bucharest).



Counties distribution of the 40th interruption cases in the hospitals distribution/suppliance with ARV drugs



■ Constanța	17%
■ Bacău	23%
■ Mureș	30%
■ Iași	30%

During the monitoring process in April-June 2004, there have been problems regarding the distribution/supplying for hospitals with the following antiretroviral drugs: Stocrin, Combivir, Retrovir, Epivir, Zerit, Norvir, Kaletra, Viracept, Abacavir and Ziagen.

In the documented cases by the field interviews/investigations in the period April-June 2004, the following ARV drugs were missing as follows: in Constanța (Zerit – in May for 10 days) and Norvir (in May and June), in Bacău (Zerit – in April), in Mureș (Combivir, Kaletra, Abacavir, Zerit, Viracept, Ziagen, Stocrin – in April, May and June) and in Iași (Zerit – in May, for 7-12 days).



## 2. SPECIAL SOCIAL PROTECTION

### 2.1 Children HIV infected and/or affected by AIDS

**D**uring April-June 2004, there have been documented **243 cases of violations of the rights of children to special social protection**, as follows:

- ✘ 95 children have not benefited of free loisir places in pupils' camps (in Giurgiu and Sibiu counties);
- ✘ 48 children are in a school abandon situation due to their health and/or their parents' will caused by their fear of the reactions of the community to revealing the diagnosis (in Sibiu, Galați, Caraș-Severin, Bacău, Neamț, Iași, Vaslui and Suceava counties);
- ✘ 45 children did not receive free transportation tickets according to the Law 519/2002 (in Constanța, Iași, Neamț and Suceava counties);
- ✘ 46 children confronted delays, unpayment and/or partial payment of the food allowance according to the Law 519/2002 and 584/2002 (in Constanța, Sibiu, Bacău, Neamț and Vaslui counties);
- ✘ 5 severely disabled children have not benefited of a personal assitent, the City Halls invoking lack of funds (in Giurgiu, Galați and Neamț counties);
- ✘ in some of the cities from Mureș county (Danes, Vânători, Crăciunești and Miercurea Niraj villages), the Law 519/2002 is not known and not applied. To prove this we have 4 documented cases.



## 2.2 Adults HIV infected and/or affected by AIDS

**D**uring the monitoring report, there have been documented **22 special social protection rights violation cases** for adults HIV infected and/or affected by AIDS, as follows:

- ✘ 10 persons contested the decision regarding getting a disability degree, due to the incompatibility between the infection doctor's recommendation and the decision of the persons with disabilities expertise committee (in Botoșani, Bacău, Galați and Suceava counties);
- ✘ 7 persons did not receive the food allocation according the Law 584/2002 (in Vaslui and Suceava counties);
- ✘ 3 persons were confronted with confidentiality violation in the social investigations carried out by the City Hall social assistants (Bucharest, 4<sup>th</sup> district City Hall);
- ✘ 2 persons have not benefited from the provisions of the Law 519/2002 (in Suceava county).

## 2.3 HIV/AIDS affected family

**D**uring the monitoring process there have been documented **20 special social protection rights violation cases** for HIV/AIDS affected families, as follows:

- ✘ 13 families have not benefited of priority to renting, building and buying houses from the state fund, according to the 519/2002 Law provisions (in Sibiu, Caraș-Severin and Galați counties and Bucharest);
- ✘ 3 families have not benefited from priority at the setting-up of a telephone service (in Galați and Sibiu counties);
- ✘ 2 families have not benefited from exemption from the payment of radio and TV subscription (in Galați and Sibiu counties);
- ✘ A parent of a seropositive child has not benefited from free services of boarding and lodging at the hospital during the child's hospitalization (in Constanța county);
- ✘ A family has not benefited from priority to connecting to the electric network (in Galați county)



## 2.4 The personal assistant of the severe disabled person (HIV/AIDS)

**D**uring the monitoring process we have documented **105 cases of violation of the rights of the personal assistant of the severely disabled person (HIV/AIDS)**, as follows:

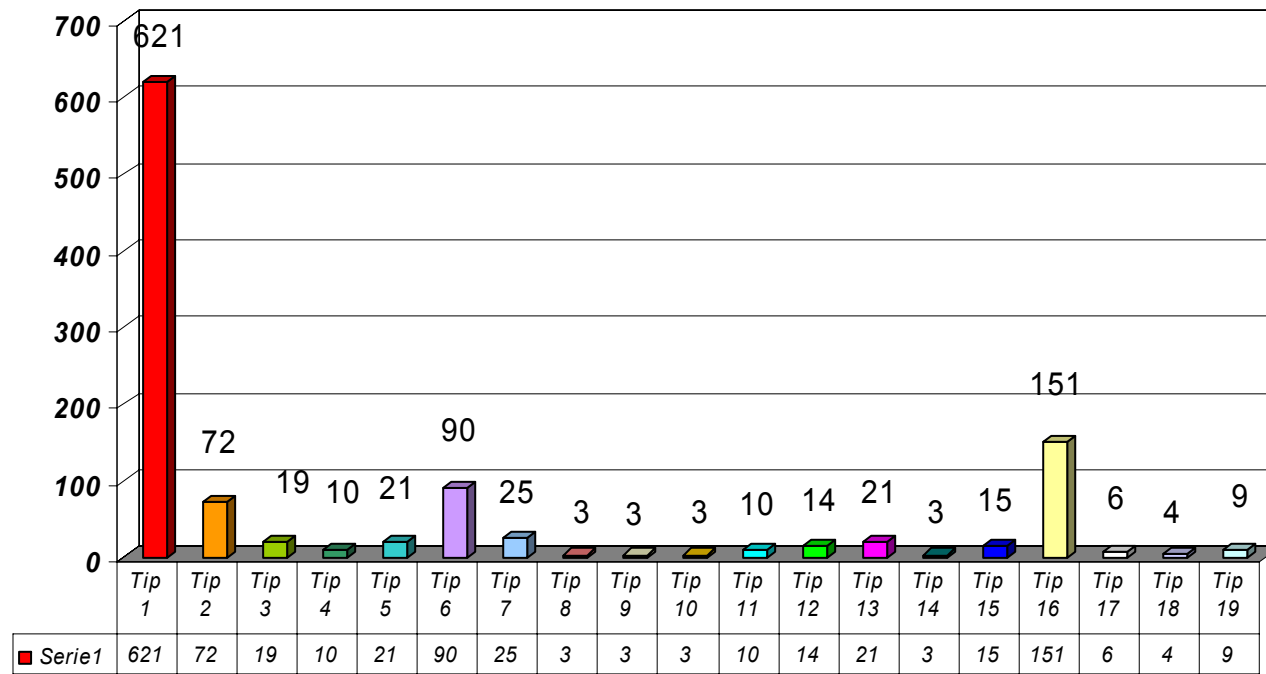
- ✘ 31 personal assistants have not received free transportation tickets according to the 519/2002 Law provisions (in Constanța, Iasi and Suceava counties);
- ✘ 27 personal assistants have not benefited from the release of a copy of their individual work contract (in Constanța, Caraș-Severin and Sibiu counties);
- ✘ 20 personal assistants have not benefited from integral payment of the salary of the personal assistants of the severe disabled person (HIV/AIDS) (in Bucharest and Constanța, Iași, Neamț and Vaslui counties);
- ✘ In 18 cases we have recorded delays in the payment of the salary of the personal assistants of the severe disabled person (in Sibiu, Iași and Vaslui counties);
- ✘ In 6 cases the salaries for the personal assistant of the severe disabled person have not been paid for a period of 1 to 5 months (in Giurgiu and Iași counties);
- ✘ One person has been refused by the City Hall to getting a work contract as personal assistant (in Galați county);
- ✘ One person has been refused in employing as personal assistant of the severe disabled child due to lack of City Hall funds (in Mureș county);
- ✘ One personal assistant has been discharged and re-employed only for a period of 6 months (in Constanța county).

### 3. APPEALS MADE BY UNOPA'S MEMBER NGOs FOR DEFENDING / PROMOTING THE RIGHTS OF PERSONS LIVING WITH HIV / AIDS

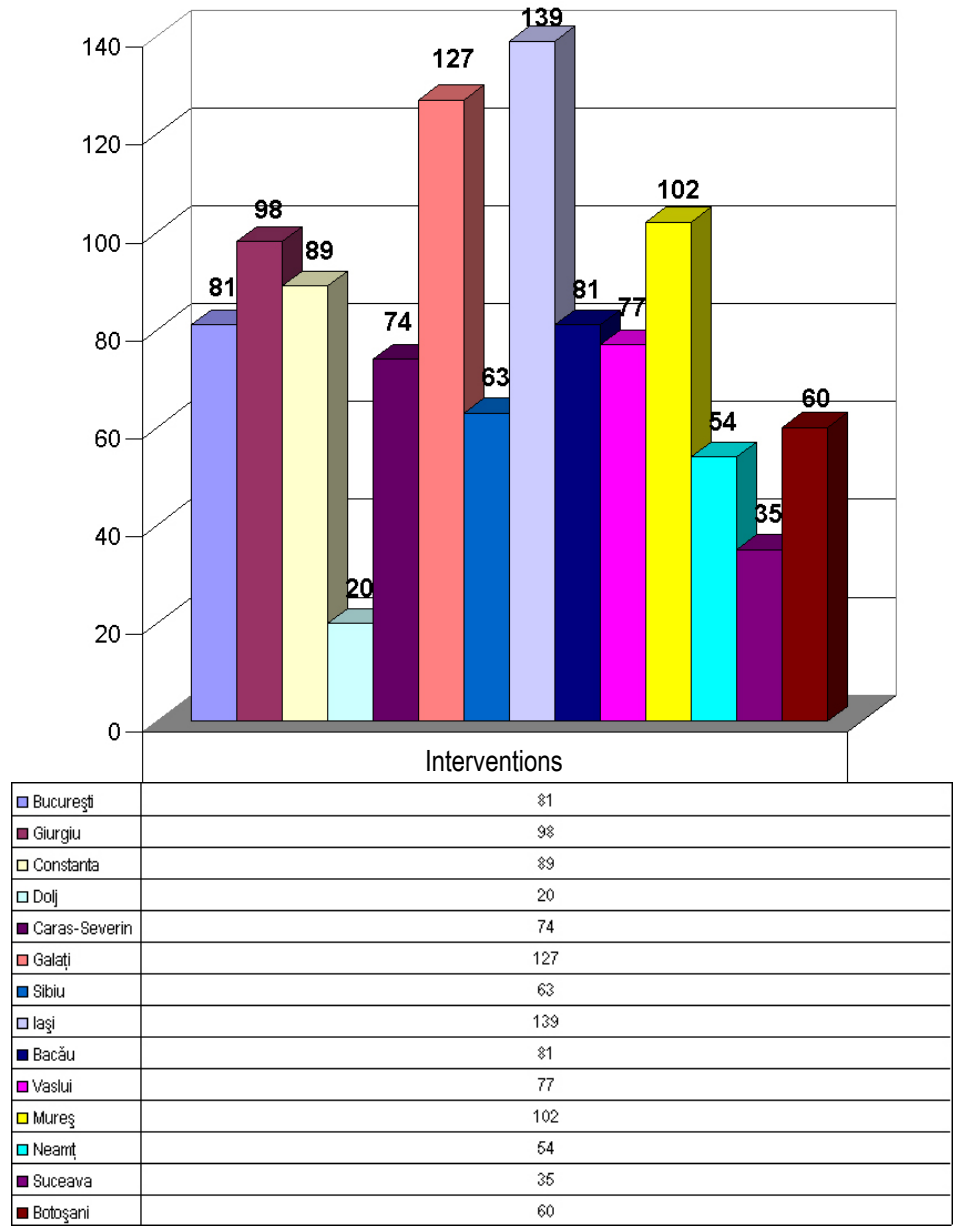
Type 01	Rights info/promotion	621 persons
Type 02	City Hall letters	72 cases
Type 03	Appeals to Public Health Department and to National House Social Assurances in order to receive free analysis collection and drugs release	19 cases
Type 04	D.P.C. letters	10 cases
Type 05	Interventions for improving the medical services	21 cases
Type 06	Files forwarded for allowance according the Law 584 D.D.F.S.S.	90 cases
Type 07	Interventions to the Expertise Committee	25 cases
Type 08	Appeals to the Romanian Post Agency (PTTR) and BancPost	3 cases
Type 09	Appeals to Romtelecom	3 cases
Type 10	Appeals to SC Electrica	3 cases
Type 11	Appeals to D.A.S./S.J.A.S.	10 cases
Type 12	Appeals to D.G.P.S.	14 cases
Type 13	Appeals to schools and the schools inspectorates	21 cases
Type 14	Appeals to the Police	3 cases
Type 15	Mass media	15 cases
Type 16	Direct support and counseling	151 cases
Type 17	Employment support	6 cases
Type 18	Appeals to other NGOs for rights violations	4 cases
Type 19	Material support	9 cases



The distribution of the interventions made by the 19 UNOPA member NGOs for respecting the rights of the persons living with HIV/ AIDS



The distribution of interventions, by counties, for respecting the rights of the persons living with HIV / AIDS, made by the 19 UNOPA member NGOs



## CONCLUSIONS AND RECOMMENDATIONS

The results of this monitoring process lead, in our opinion, to the following conclusions:

- ✘ **59%** of all the investigations have documented cases of rights violations of persons living with HIV/AIDS;
- ✘ the fact that **50.5%** of all the rights violation cases are related to “**health**”, show that **the access to treatment and medical care** remains the most important institutional problem that HIV positive persons are facing, in Romania;
- ✘ the worst cases documented in this field focused on “**the repeated discontinuity of the antiretroviral treatment (for 7-12 days)**” (in Constanta, Bacau, Mures and Iasi counties);
- ✘ **85%** of the rights violation cases documented in the field of “**treatment and medical care**” are due to poor management of the sanitary system and to the insufficiency of the funds allocated to treatment;
- ✘ an important part of the cases of rights violation (such as: the refuse of dentists services, the access to the public school) is due to discrimination and stigmata that is attached to the statute of HIV infected person and as long as this attitudes will persist, the chances to defeat the virus will be seriously affected;
- ✘ cases of rights violation in the field of “**special social protection**” are mostly due to the lack of interest of the local authorities regarding HIV/AIDS issues as well as to the poor management of the local funds.



## Recommendations:

- ✘ the Romanian Ministry of Health should simplify the procedures of receiving the kits and the necessary reactivities for the specific analysis in the clinical monitoring of HIV/AIDS patients' treatment;
- ✘ the hospital distribution/supply management with ARV drugs should be immediately improved in order to eliminate the blockings and the possibility to stopping the antiretroviral treatment;
- ✘ the staff from the administrative and sanitary system should be better trained in working with HIV/AIDS patients and efforts must be made to eliminate the discriminative attitudes in this system;
- ✘ the info level and the society's capacity of answering to the HIV/AIDS challenge in Romania must be improved through info and awareness campaigns in order to create a positive opinion flow for respecting the rights and the equality of treatment for persons living with HIV/AIDS;
- ✘ the education system must play a more important role in preventing and fighting the HIV/AIDS epidemic and the discrimination towards the persons living with HIV/AIDS, through intensifying and improving health education promotion in the scholar curricula and through encouraging partnerships between schools and NGOs.

