National Center for Community Services
Qendra Kombëtare për Shërbime Komunitare

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World Health Organization

"DON'T FORGET ABOUT US"

Children Living with HIV/AIDS in Albania

INSTITUTI I SHENDETIT PUBLIK
"Hulo Hajdëri"

SHOQATA SHQIPTARE PLWHA

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In 2009, considering the increasing number of children infected with HIV, experts from the Institute of Public Health undertook a qualitative study to evaluate their treatment and life conditions.

Afterwards several data from this study were discussed with civil society actors, such as NCSS PLWH association and UNICEF. In 2010, NCSS, supported by UNICEF, and in cooperation with ISHP undertook actions that were never implemented before in our country, based on open and concrete discussions about HIV and problems related to it, with the presence of affected people in local areas.

A set of informing meetings were organized with health, education, social services and local governance structures, regarding HIV/AIDS in general and infected, affected and endangered children in Albania. Subsequently round tables were organized with both the participation of health, education, social services, local governance and prefecture structures and infected children's parents. During these meetings identified problems and existing ways of resolving them were discussed intensively

Other qualifying meetings were organized within the health system as well as analysis undertaken on existing social, educational, and legal politics seen from the point of view of protecting, respecting and complying with human rights. A number of findings have been identified and many recommendations have been prepared based on these assessments and meetings. This report doesn't aim to resolve all the problems facing children with HIV in Albania, but for the first time it addresses them, showing that major problems do not depend on the numbers but on the depth and vulnerability of affected persons. It is guided by the principle that every child is

worth more and they should all have equal opportunities to start a decent life.

This assessment would not have been possible without the dedication of PHI's experts, cooperation and dedication of NCCS and the People Living with HIV Association (parents and relatives of children living with HIV). Opinions, thoughts, experiences, concerns and problems they encounter in their daily lives, made it possible for us to come closer to the real situation and environment these children live in.

A special gratitude goes to the WHO and UNICEF office in Tirana for their financial support of the project: "Capacity strengthening for local communities where children living with HIV / AIDS are currently living", the core of which is this assessment, and in particular to Mrs. Alketa Zazo (Responsible for Youth Health Programs/UNICEF) for the continuous contribution during the evaluation, in professional as well as human terms.

Special contribution in assessing and identifying the needs of Children Living with HIV / AIDS, was given by other "actors", participants in meetings, round tables or direct interviews; teachers, school directors, doctors (pediatrician , epidemiologist, obstetrician, gynecologists, nurses, specialists of DPHs in districts), social workers, psychologists, specialists of economic and social safety net office, representatives of prefectures and municipalities, representatives from civil society and even elementary and secondary school pupils.

Also a special thanks goes to the prefect of Kukes district, the mayor and prefect of Elbasan, Mayor of Fier, mayor of Peshkopi and all local government structures, education, social and health service in Kukes, Tropoje, Rubik, Durres, Tirana, Fier, Lushnja, Vlore, Elbasan Dibra and Belsh.

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ACRONYMS

AIDS	ACQUIRED IMMUNE DEFICIENCY SYNDROME
ART	Antiretroviral Therapy
ARV	Antiretroviral
DHS	Demographic Health Survey
PHD	Pubic Health Directory
ELISA	Enzyme –Linked Immunosorbant Assay
HIV	Human Immunodeficiency Virus
IEK	Informing- Educating - Communicating
PHI	Public Health Institute
HCII	Health Care Insurance Institute
KEMP	Commission of Expertise Medical-Labour
MARA	Most at Risk Adolescents
M.SH.	Ministry of Health
MTCT	Mother to Child Transmission
NPO	Non-profit Organizations
PLWHA	People Living With HIV/AIDS
RAR	Rapid Assessment and Response
RHS	Reproductive Health Survey
QSUT	Tirana University Hospital Center
UNAIDS	United Nations against AIDS
UNICEF	United Nations International Children's Emergency Fund.
VCT	Voluntary counseling and testing

1. Introduction

Hearing the phone ring, detached me from my everyday work, that gloomy day filled with raindrops and clouds. They told me a child with HIV, diagnosed a while ago in an orphanage was refused to be hospitalized in the largest University Hospital Center in the country.

That child left in the car and the fear of the medical personnel for the first time exposed me to a different reality, exactly in 2003 when many of us thought we already knew the problems of HIV / AIDS in our country.

This was followed later on by the confrontation with a hostile environment, lack of professionalism and information and discrimination towards HIV/AIDS positive children. I also faced problems with proper social care towards children from the same family.

Also in those hot summer days of 2005, I can't forget how difficult was for me to pick up the telephone and inform parents that the results of their children's examinations were not good and they had to repeat them.

I had to explain that the blood which was supposed to save their children's life was now the reason of an enormous problem. I can't forget how much I wished at the time for all the results to be a mistake; for all the children, not only the beautiful little girl from Elbasan, who buckled a little bag and a doll in her hand while we were taking the analysis.

Further problems clearly showed us how weak we were on the health as well as social aspects of the problem.

As if all this wasn't enough, we were shocked when a colleague called accusing loudly and making us responsible for spreading HIV. He told us that he couldn't allow his child frequent a school with a child, whose parents were infected with AIDS, even though the child was not infected. Moving ahead, ignorance, fear and stigmatization accompanying this virus, adding here the open discrimination and violation of HIV positive diagnosed children's rights have been the main reasons for neglecting their basic needs.

The right to education is basic for every child. Nevertheless the major part of HIV positive children have faced violations of this right, taking often the form of an expulsion revolt from parents whose children are not affected by this virus. Later on a range of problems appeared with acceptances in kindergarten and schools inside and outside of Tirana, where parents, kindergarten educators and teachers were mobilized by fear and didn't understand or forgot they were stigmatizing and discriminating innocent children, demonstrating that the system didn't have appropriate mechanisms yet.

Almost every day we face problems with medical treatment of HIV positive children beginning with delays in antiretroviral medicines, lack of mechanisms to provide necessary free medicaments on (opportunistic infections), lack of financial aid from state institutions, the financial burden of these families due to continuous trips to Tirana, lack of other supporting services and many problems related with providing a modest lifestyle and the upbringing of their children.

At the time this report was written a child died with AIDS as a result of the late diagnose and another was born infected with HIV since one of the parents was known to be infected since 2006 and the mother got infected during these years, regardless of our existing prevention programs, she declared that: **"I had two choices: either**

break up with my husband, or get this infection" *ignoring that an infected child could be born.*

This fact clearly illustrates how many problems are there still to be resolved and how far we are from what Ebube Sylvia Taylor, the 11-year-old children asked during a meeting of world leaders: **No child should be born with HIV, no child should be orphaned due to HIV and no child should die due to lack of access to treatment.**

It also indicates that focusing on certain vulnerable groups isn't the only key to success.

2. PURPOSE AND METHODOLOGY

The report we are presenting reflects the current situation of children infected and affected with HIV / AIDS. The purpose of this study is to document data on the situation, protection and support offered to children infected and affected with HIV / AIDS. It also aims at collecting data on their medical, social and psychological treatment, rates of discrimination and the role of the Convention on Children Rights and Albanian legislation, identifying related problems, as well as contributing on building a positive local environment for children living with HIV and their families.

2.1 Specific objectives

Specific objectives of this study are:

1. To identify the situation on the ground. Proving, reviewing, analyzing and documenting information related to the situation of children infected and affected with HIV in priority areas such as health care, education, social and psychological support, protection, legal aspects, stigma and discrimination and socio-economic conditions.
2. To review, analyze and document data on interventions conducted in the above areas and to focus on identifying the impact or weaknesses of these interventions.

3. To analyze data based on the above mentioned facts, describing the positive impacts and gaps or weaknesses in the development of relevant programs and interventions.
4. To formulate and prioritize practical recommendations in the above areas after collecting and processing data, discussions on local and national level and reaching a consensus on plans that national authorities and local communities should develop to improve the environment and to ensure that these children and their families have a healthy lifestyle.

Analysis of factors affecting these medical problems:

Current data indicates that the way children are affected, changes and is based on different factors such as:

- Epidemiology factors related to the spread of epidemic, factors that determine which children become infected, living in households affected with HIV or are orphaned for this reason;
- Family factors, including not only the status of their parents or their relatives about HIV, but also levels of poverty, socio-economic status and access to health care for the child;
- Cultural and community factors related to child care practices, skills of families and communities to provide care and support to children living or infected with HIV as well as their coherence;
- The opportunities and capacities of government, communities and organizations to respond effectively.

2.2 Definitions and terminology on children

Although it often seems that the terms used explain themselves, in this study the term "child" is used for all ages ranging from 0 to 18 years (as defined by the Convention of Children's Rights and the

Albanian constitution), although in Albania the term "child" is used for ages ranging from 0 to 14. All services are organized based on this definition. Regarding children's stages of development we used previously defined terms such as:

1. Newborns: Includes the category of children up to 12 months, representing a period of rapid development and complete dependence on parents and guardians, their vulnerability is high and often the first hours and months are very important.
2. Early childhood: Children up to 5 years, a period characterized by rapid physical and mental development, with a lesser risk of infection compared to newborns.
3. Middle childhood: Children from 5 to 10 years old. This phase includes development towards adolescence.
4. Adolescence: Early adolescence up to 15 years old, and late adolescence up to 18 years old, are phases characterized by a quick physical and mental development and has a higher risk on psychological impacts and dangerous behaviors

By choosing these age groups, various challenges become clearer that have to cope with children and systems for all problems and categories and where each phase has needs, risks, vulnerability and its demands and requires different intervention possibilities.

Regarding the definition used for HIV / AIDS in this study we have used the adapted classification by Tarantola and Gruskin and USAID / UNICEF:

1. Children infected with HIV / AIDS, including all children who are diagnosed with HIV, living with HIV / AIDS or have died from HIV/AIDS. Children living with HIV are therefore all those diagnosed and living with HIV.
2. Children affected by HIV / AIDS when family members are infected or have died from HIV / AIDS. Being affected:
   2.1. directly, when one or both parents are infected or have

died from HIV / AIDS or

2.2. indirectly, when living in households and communities with affected people as brothers or sisters and other relatives with HIV

3. Children orphaned by AIDS are children whose one or both parents died from AIDS
4. Endangered children from HIV / AIDS are those whose behaviors and situations put them in a high risk of exposure to the virus.

In this study we have tried to focus our attention more on 1.2 and 3.2 groups despite the limited opportunities during the study, we have evaluated the impact of this group, in order to enable later the evaluation of other groups, with different sizes (given the low prevalence in the country and complex situations).

2.3 Methodology

The evaluation of the current situation is done through a guiding questionnaire to assess the needs of children with HIV based on USAID / UNICEF, WHO, Council Popo (bibliography) presented in Annex 2. Then in the organization of focus groups in families, communities, local authorities structures and health services (according to Annex 3) and their analysis.

Assessment of children's rights, legal aspects, stigma and discrimination is performed by adopting the instruments presented by Tarantola and Gruskin, UNAIDS, USAID / UNICEF.

The project was organized in two phases:

Phase I:

Situation aanalysis, covered by PHI in collaboration with People Living with HIV / AIDS Organization. This analysis is further

deepened during the second phase of the study, through focus groups organized with families of children with HIV positive, QSUT's medical staff' who deals directly with the treatment of these children, as well as round tables in the districts.

It is well known that HIV / AIDS is a very delicate health issue directly related with the great stigma that accompanies it. Often it is quite difficult to have full details of persons reported as HIV positive. This situation was faced even in the case of HIV positive children, where addresses and contacts of them were missing, (you have to pick an element however small it is, that maybe before the beginning of this study was thought of having no value in the random investigation and then follow them up in achieving results).

Phase II:

During this phase the activities implemented with the participation of UNICEF and NCCS, included:

Activity I - Training in Tirana with epidemiologist and psychologist where children infected with HIV / AIDS were identified. These representatives of the districts were trained to be prepared for round tables management in the districts according to the curriculum presented in Annex 8. (See the agenda of the first meeting)

Activity II - Organization of round tables in the districts where there are children living with HIV / AIDS. It was compiled, in each of these tables, an agenda that contained:

1. Presentation of the epidemiological situation of HIV / AIDS at the national level.
2. Analysis of epidemiological data for each district.
3. Presentation of the data assessment on the socio-economic HIV positive children in respective districts, always reserving their confidentiality (based on the first phase).

4. Discussion and clarification of the law, what are the possibilities offered by the law in order to create an enabling environment.

These tables were organized respectively in the districts of Kukes, (Tropoje, Kukes-these two districts were involved in a meeting at the prefecture level), Bishop, Rreshen, Elbasan, Fier, Lushnja, Vlora, Shkodra, Durres, Tirana

Activity III – Discussion of results at the central level with various actors, analysis of the data and their coverage in the joint report with all findings and recommendations arising from the activities of the two above phases.

3. Section 1: ABOUT CHILDREN WITH HIV/AIDS IN THE WORLD AND ALBANIA

3.1 Children with HIV/AIDS in the world

HIV / AIDS is one of the major health problems where AIDS-related diseases constitute one of the most important causes of death in the world. According to the forecasts they will continue to be one of the main causes of premature death even in the next ten years.

From the report data on world epidemic AIDS of UNAIDS in 2010 it is estimated that about 33.3 million people were living with HIV in 2009 and among them 2.5 million (1.6 million-4.3 million) were children under 15 years old. Also around 2.6 million (2.3 million -2.8 million) new HIV cases were recorded in 2009. Meanwhile as a result of increased access in prevention services from mother to child it is seen a decrease in the total number of children born with HIV.

Only 370 000 (220 000 -520 000) new cases were diagnosed in 2009 thus indicating a fall of 24% compared with five years ago. The number of deaths related to AIDS has decreased from 2.1 million (1.9 -2.3 million) in 2004 to 1.8 million (1.6 - 2.1 million). This reduction reflects the possibility of treatment and support. However, unfortunately, death rates continue to rise in Eastern Europe.

Deaths among children under 15 are also decreasing. Estimates show that 260 000 (150000-360000) died from AIDS related diseases

in 2009, 19% less than what was evaluated in 2004. Once again this trend reflects the extent of services to prevent transmission of HIV. Around 16.6 million children under 18 have lost one or both parents from AIDS.

Most of the children living with HIV / AIDS and those affected by this disease live in Sub-Saharan Africa (90%).

Central and Western Europe where Albania, and other countries of South East Europe are part of, according to epidemiological analysis of UNAIDS, in this countries it is found the lowest number of children living with HIV, about 1400 (<1000 -1800), followed by North America with 4500 (4000 -5800) and East Asia 8000 (3600 -13,000), Caribbean (8500 -26,000), while in Central Europe and Central Asia, live 18 000 (8600 - 29 000) children infected with HIV/ AIDS. HIV / AIDS epidemic has appeared relatively late in Albania compared to other European countries.

If we refer to the figures of EURO HIV where it is reflected the surveillance of HIV / AIDS in Europe according to WHO and the ECDC, Albania is part of Central European countries together with the many East European countries (Albania, Bosnia and Herzegovina, Bulgaria, Croatia, Macedonia, Montenegro, Romania and Serbia) and other EU countries (Czech Republic, Hungary, Poland, Cyprus, Slovakia, Slovenia) and Turkey.

This region has the lowest numbers of new cases of HIV (1.4/100000 per inhabitants) but with a higher number of cases in younger people compared to Western and Eastern Europe (18.9%). Compared to other countries of the region, Albania appears to have a more pronounced trend related to the increasing number of cases due to transmission from mother to child; also children infected by blood transfusion in recent years, although detailed data about the route of transmission by age ranging, are not specified for this region.

3.2 Children living with HIV/AIDS in Albania

In December 2010 the total number of cases diagnosed and reported with HIV / AIDS in Albania was 408. Only in 2011 43 new cases of HIV / AIDS (Figure 1) were reported

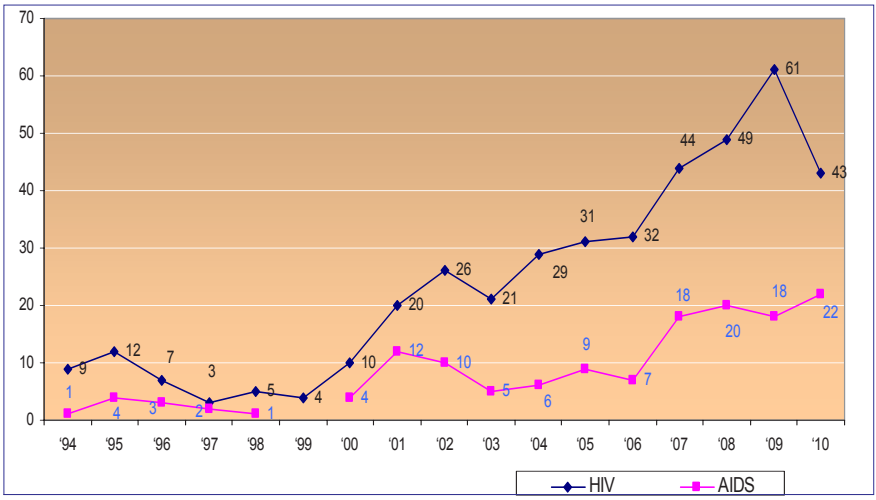


Chart 1. DISTRIBUTION OF HIV/AIDS CASES IN YEARS, 1993 – DECEMBER 2010 ACCORDING TO THE TIME OF DIAGNOSIS

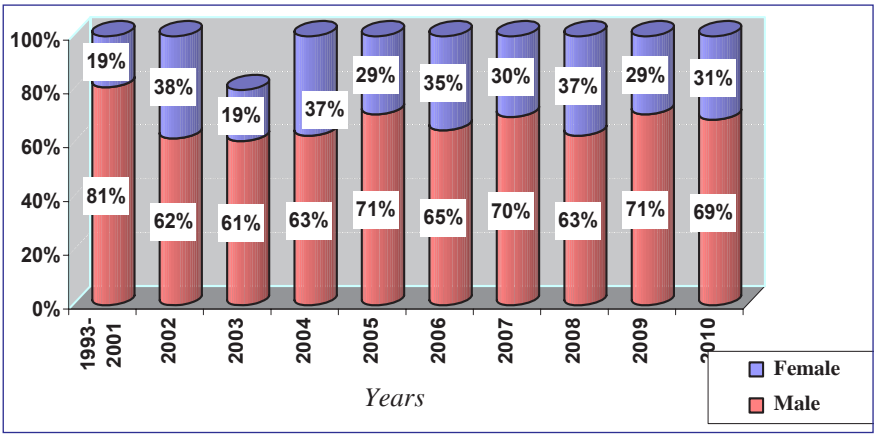


CHART 2. DISTRIBUTION OF CASES ACCORDING TO GENDER IN YEARS, 1993 - 2010

The first case diagnosed with HIV in our country is reported in 1993. In more than 90% of the cases the way of transmission is through sexual intercourse (82 % heterosexual and 10 % bisexual) and the most affected group age is 25-45 years old. Since the beginning of the routine blood control in 1993, 42 donors had HIV positive results, but HIV transmission through infected blood is confirmed in 11 cases, transmission from mother to child (MTCT) is confirmed in 15 cases.

The first diagnosed child with HIV/AIDS was in 1997. Up to December 2010, 21 children infected with HIV / AIDS were reported, 15 of whom are infected through the vertical transmission from mother to child, while 6 of them are infected through blood transfusion. Most of the kids were in the period of HIV infection but in 2010 a case of AIDS was diagnosed in a child, the disease was in a very late phase and therefore he died several weeks later.

Out of 21 infected children, 3 of them died due to AIDS. Up to now kids comprise 5.3% of persons living with HIV / AIDS and 4.9% of persons infected with HIV/AIDS. Transmission through blood is proved in 6 cases and in 15 other cases from mother to child.

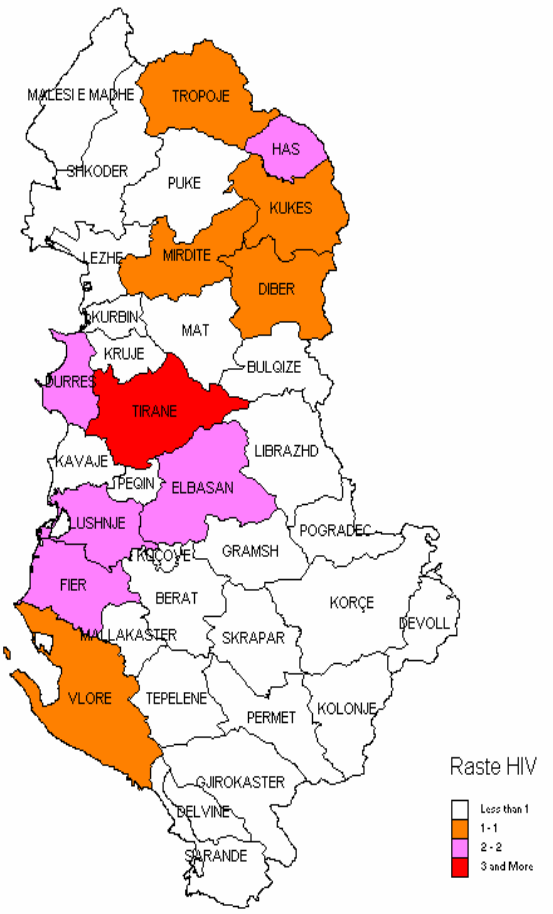
After the first case of HIV transmission from mother to child, the other cases appeared in 2003 and later those from blood transmission, primarily to persons who have obtained many blood transfusions due to another disease they used to suffer from.

Seroprevalence studies on pregnant women do not provide valuable data on countries with low prevalence. According to two seroprevalence studies conducted in 1999 and 2003; at about 500 pregnant women who were randomly selected across the country this prevalence is zero, so no case was diagnosed with HIV at a time when the prevalence of hepatitis B remained high about 8% in this population group.

Despite the evident improvement of data and assessment studies,

yet we do not have accurate estimates of the number of children infected with HIV, beyond the number of assessments recorded or those who are sick with AIDS. Even though this number is considered small it reflects HIV/AIDS situation in our country with low prevalence, but simultaneously through identification of transmission routes it highlights our two main public health problems, **lack of programs for transmission from mother to child and fragile systems that provide secure blood.**

Distribution of HIV positive cases by district age-group 0-15 years (at the time of diagnosis)



3.2.1 Sample of the study

19 HIV positive children who live with HIV/AIDS were part of this survey. Below there are some demographic data related to the group age at the time of assessment and diagnosis. Most of the children live in rural areas.

	Group Age - years					
	<1	1-4	5-9	10-14	<18	Total
Cases	0	4	7	4	4	19
(%)	(0%)	(21%)	(37%)	(21%)	(21%)	

Table 1/a: Number of children living with HIV according to group age at the time of the interview.

	Group Age - years					
	<1	1-4	5-9	10-14	<18	Total
Cases (%)	1	9	6	1	2	19

Table 1/b: Number of children living with HIV according to group age at the time of diagnostician

Gender	Male	Female	Total
Cases (%)	12 (63%)	7(37%)	19

Table 2: Distribution of chidren who are living with HIV according to Gender

Domicile	Urban	Rural	Suburbs	Total
Cases (%)	6(32%)	12 (63%)	1(5%)	19

Table 3: Distribution of chidren who are living with HIV according to establishments

After the first case of HIV transmission from mother to child, the other cases appeared in 2003 and later on those from blood transmission.

Nr.	Reporting year	Nr. of cases
1	1997	1 case
2	2003	4 cases
3	2004	1 case
4	2005	3 cases
5	2006	3 cases
6	2007	3 cases
7	2008	1 case
9	2009	2 cases
10	2010	1 case

Table 4. : Distribution of chidren who are living with HIV according to the reporting year

Nr.	Reporting year	Nr. of cases
1	1997	1 rast
2	2003	4 raste
3	2004	1 rast
4	2005	3 raste
5	2006	4 raste
6	2007	4 raste
7	2008	1 rast
9	2009	2 raste
10	2010	1 rast

Table 5 . Distribution of HIV positive children cases according to the reporting year .

Table 6.
Distribution of HIV positive children cases according to the possible year of infected

Nr	Reporting year	Nr. of cases
1	1995	1
2	1996	2
3	1997	1
4	1998	2
5	1999	1
6	2001	2
7	2002	2
8	2004	1
9	2005	1
10	2006	2
11	2007	1
12	2008	1
13	2009	1

Table 5&6

Nr	Year of diagnostification	Year of infection	Period of diagnose settelment
1	1997	1996	1 year
2	2003	2002	1 year
3	2003	2001	2 years
4	2003	1995	8 years
5	2003	2001	2 years
6	2004	1996	8 years
7	2006	2002	4 years
8	2006	2004	2 years
9	2006	1998	8 years
10	2007	2006	1 year
11	2006	1998	8 years
12	2007	2005	2 years
13	2007	2006	1 year
14	2007	2007	Within the year
15	2008	1999	9 years
16	2009	2008	1 year
17	2009	2009	Within the year
18	2010	1997	13 years

3.2.2 Key questions of the study

In this study parents or relatives of HIV positive children were interviewed. The conditions in which these children live were specifically assessed. The instrument used in this case was a questionnaire consisting of semi-structured and open questions that allowed respondents to freely express their opinions regarding the more subtle and complex issues of HIV / AIDS.

Except the part of general information for the child and all his family (age, education, employment), the questionnaire included open questions about the experiences of everyone, the effects of this disease on their daily life, attitudes of the community to the fact, their diagnoses on health, social and psychological services, what they would like to change and what are their plans for the future.

4. Section 2: MEDICAL TREATMENT FOR CHILDREN WITH HIV/AIDS

Medical care and treatment for children with HIV / AIDS are offered only at the pediatric service of Tirana University Hospital Center (QSUT), while children older than 14 are treated at the Infectious Disease service for adults in the QSUT.

When talking about **vertical transmission (15 cases)**, it often happened that the child's health problems led to his diagnosis as HIV positive case, and then the mother was diagnosed (or sometimes both parents). But it has happened differently when parents are diagnosed early, and child / children after.

Children infected through the blood or its byproducts (6 cases) are divided into two sub-groups;

1. The first subgroup belongs to thalassemic children who are subject to frequent blood transfusions (3 cases),
2. The second subgroup that in the two cases have received blood transfusions only once, while the third case within this subgroup presented with complex, having taken more than once a blood-subproducts.

In cases of infection from blood, 3 cases, the diagnosis was made due to the epidemiological investigation, for two cases were

health problems that lasted *for years and a case, a thalassemic child, was diagnosed abroad (Italy) while he was waiting for spinal transplantation.*

Late diagnosis is encountered even in cases of children infected with HIV, a fact that poses an urgent task for our healthcare system, such as the creation of a National Program for Prevention of Transmission from mother to child. Diagnosis time setting ranges from 1 - 13 years. Below there are data on the time of establishing diagnosis for 21 cases of children infected with HIV / AIDS in Albania:

- ✓ 2 cases within the year,
- ✓ 5 cases in a year,
- ✓ 4 cases in 2 years
- ✓ 1 case in 4 years
- ✓ 4 cases in 8 years
- ✓ 1 case in 9 years
- ✓ 1 cases in 13 years
- ✓ 3 cases are not exactly known but it is thought that they are diagnostified after 2-3 years.

Late diagnosis has had not only serious consequences on the child's health, but it also has had a high financial cost for families going from hospital to hospital for years. Two cases were diagnosed abroad (Austria and Italy) while the other ones inside the country.

In general we may say that there were problems with the treatment of HIV positive children, but it's worth saying that **not always the treatment scheme is applied.** Medication planning is made by pediatricians of this service. So far there are 16 HIV positive children w treated with antiretroviral therapy. Two children are extracted from treatment, one case for several years, while the other a few months ago. Family members communicate by phone

with the doctors, before arriving in Tirana to take medication, which is taken once a month. The law provides reimbursement to these persons for transportation costs, but in fact this has never happened, that's why interviewed families have appreciated those cases when doctors provide treatment for a longer period than 1 month.

The major problem for these children is the provision of drugs used for treatment of **Opportunistic Infections** (OI), which should be bought by their own family. In those cases, where the family doctor is aware of the child's HIV status, he has tried to help family members, admitting to have done mistakes in the fulfillment of drugs prescription, a fact which has been well known even from the ISKSH representatives.

Particular attention is required for thalassemic children. **Lack of blood** is identified by some of their families, especially in the hot summer season. They have to go 2 times a month at the blood bank in Lushnje to obtain blood and once a month they have to come to Tirana. Transportation constitutes higher living costs which burdens further their financial problems.

According to the law on HIV / AIDS, persons less than 18 years old infected with HIV / AIDS, should receive social assistance in cash or services, when they are unemployed, but in fact no one has received this kind of support.

Regarding KEMP, 12 children receive this assistance (KEMP) consisting of 8700 ALL, 3 kids do not get it because of identification complexes; a child does not take because his relatives (his parents do not live) were not aware of this fact.

Another problem that worries parents of HIV positive children is the "hotel" during the time their children are hospitalized. Often pediatrics has offered them the possibility for both parents of the

child to stay in a room with their child and this made them not want to send their child (after the age of 14) at Infection Diseases Service for adults.

At the ISKSH book, AIDS is not classified as a special category, that's why suggestions of ISKSH specialists, indicate that family doctors have violated the law to help HIV positive children.

During all the meetings held in the districts it is shown that there must be a greater relation between the center (University Hospital Center) and base (services in the districts) in terms of updating the acquaintances for the treatment of HIV positive persons (particularly children). The psychologist at the Health Service must deal constantly with HIV positive children and their families by providing the needed psychosocial support for this group.

These children and their parents need a specific psychosocial support, which is why at health institutions (pediatrics and infectious disease service at the University Hospital Center) regarding the treatment of these children, you can find nowadays psychologists who deal directly with counseling and psychosocial support for these children and their families.

We appreciate:

- ✓ Free treatment for persons infected with HIV/AIDS.
- ✓ The providing of antiretroviral therapy for HIV positive people since 2004.
- ✓ Conducted examinations such as viral load, counting of CD4 which is directly linked with the evaluation of clinical status of persons infected with HIV
- ✓ The support provided by the PLWHA Association for HIV-infected persons
- ✓ The establishment of VCT centers at the prefecture level

There are, nevertheless, deficencies and problems like:

- ✓ Late diagnostification of children infected with HIV
- ✓ Lack of a special center for these children makes family members and relatives go from one hospital to the other.
- ✓ Lack of medicines for the treatment of OI
- ✓ Restatement of the ISKSH Law
- ✓ Knowing the Law of HIV / AIDS and its implementation.
- ✓ Pregnant women aren't tested for HIV
- ✓ There is a gap between Services (dealing with the handling and tracking of PLWHA) in the University Hospital Center and respective services in districts.
- ✓ The need for capacity building and empowerment in terms of psycho-social support, this service is provided to all health institutions where PLWHA are treated and especially children infected with HIV.

5. Section 3: CHILDREN WITH HIV/AIDS AND EDUCATION

Based on **Law No. 9952, of 07.14.2008 "For prevention and control of HIV / AIDS",** in paragraph b of Article 8, children with HIV / AIDS in Albania enjoy their right to education in all educational institutions.

Currently we can say that from 19 children who are involved in this evaluation there are:

2 cases or 11% attending preschool,
8 cases or 42% following elementary school,
1 case or 5% following the secondary education,
1 case or 5% following higher education
5 cases or 26% are at home
1 case or 5% is abroad
1 case (5%) died last year in 2010, after being involved in our study.

Some of these children have experienced problems of stigma and discrimination, in an age when they still didn't know the meaning of these words, by not being accepted in schools and kindergartens (26% of them). The other part, isn't faced with these problems, not for the fact that the surrounding environment is less "stigmatizing" but because their HIV status is kept confidential and not recognized

by the surrounding community. Some parents have claimed that if the teachers will know about the child's HIV positive status, they will change their behavior and attitude toward them.

For cases (5 of them) who are at home we can say that:

2 are young and are not in an age of going to kindergarten, parents or relatives take care for them;

1 lives in the village and doesn't attend kindergarten;

2 cases belong to thalassemic children, where one does not attend school for health reasons even after his two-year effort, while the other child has no chance, because in the village where he lives there is no high school. This fact and identification of the girl as a person infected with HIV (after the announcement in the Media from her parents) has caused her closure in her modest house, despite her great desire to get educated,

Difficulties for thalassemic children infected with HIV / AIDS are several times larger compared with other infected children and that's why they require special attention. From the round tables held in the district of Fier, where two thalassemic children have been reported, one of the representatives from the Local Government said:

"Fier district has many thalassemic patients, that's why we should pay close attention to this group that is subject to regular blood transfusions. It is a fact that these children cannot attend school like other children, but on the other hand with the instructions provided by MOE "school can go to these children", offering individual education.

Even in other meetings, it has been highligheted that "the school is the best place serving as a point of awareness for the population, as it brings her close to a large part of the community, pupils, parents and relatives." "Cooperation between the DAR and DSHP should continue and themes that are developed in the ninth grade will probably be better referred to by doctors and teachers."

What has attracted our attention during all meetings is the demand (especially from representatives of educational structures) that teachers should recognize the student's positive HIV status. Likewise it is evidenced the need for teacher's training regarding universal preventive measures for HIV / AIDS.

For several years, in elementary and high schools functions a student's advice office, but it appears that the service is not sufficient, as a psychologist cannot provide efficient service for 1800 students, let alone pay special attention and giving advices and treatment to children living with HIV.

In Article 16 of Law "For prevention and control of HIV / AIDS", it is clearly stated the obligation of public or private educational institutions:

1. In cases where the pupil or the student is living with HIV / AIDS, educational institutions, public or private, are not allowed:

a) to oppose his admission in this institution;

b) to take disciplinary action or to exclude it from the institution because of HIV / AIDS.

2. Educational institutions, public or private, should not become an obstacle to the pupils or students to do HIV testing or to take his score.

This law should be presented in all the Education Departments to prevent in the future situations of stigma and discrimination of children with HIV / AIDS in educational institutions, as has happened so far.

6. Section 4: SOCIAL AND PSYCHOLOGICAL ARE (Group considerations)

Relatives of HIV positive children in need of psychosocial support (assisted by specialized psychologists) and making them able to speak with their child regarding problems of HIV / AIDS, in order to prepare them how they will make this fact known to their child.

The role of a social worker, psychologist or sociologist remains necessary in this category to enable these children and their families that their health problem shouldn't be an obstacle in being equal to others.

Social services are lacking and the infected or affected with HIV / AIDS are once more victims of stigma and discrimination.

Despite the entry of a psychologist or social worker in our health and education system, we can say that the social care and protection they provide, remains vague. There is a need for periodical training for psychologists and social workers who work in schools or in health institutions.

There is an observed lack of guidelines regarding testing and counseling for children and adolescents. Testing for HIV continuous to be not very common, in order to attract as many teenagers at counseling and testing offices (VCT) established in regions.

7. Setion 5: HOUSING, EMPLOYMENT AND SOCIO-ECONOMIC SITUATION OF HIV/AIDS CHILDREN'S FAMILIES

As indicated above, in the first phase of this study an assessment of socio-economic conditions of families with children infected with HIV / AIDS was carried. For this purpose the working group visited their families and evaluated elements such as housing, employment and socio-economic situation of families with HIV positive children. Moreover, **poverty** is added in their problems, which when mixed with "contempt" of this disease seems to be worse than the disease itself.

Housing, is a problem that hardens their living conditions Often their families first have encountered stigma from within the family members, so they are forced to be isolated within a room (a case where in a room are living three HIV positve people). *"We were living together with my husband's family, but when the latter became aware for the three of us, they isolated us in a room. This room should serve as a living room, kitchen and bedroom for us and our little child."*

In two other cases, families have preferred not to share this problem with the husband's parents, because they would not like to be found in the same situation.

Another case is that of a family composed of 9 persons, 2 of them are HIV positive, in a remote mountainous area, blocked by snow during the winter season, who live in a house damaged by earthquake where "2 rooms seem to function". This family would like very much to depart from its origin (and probably more because of the stigma and discrimination that ranks first in the "troubles" of that family) in order to be closer to the service offered in QSUT, but this thing at the moment seems quite hopeless.

We observe that a large proportion of parents of HIV positive children, are unemployed, which makes even more difficult facing the economic, psychosocial and emotional problems accompanying each step of HIV / AIDS. In none of the cases were not found any mother or father employed in the state system, unemployment prevails. This probably relates to the fact that the large percentage of these children (63%) lives in villages where access to employment is minimal, but certainly the stigma and discrimination against HIV / AIDS are still a barrier that prevents these people to knock in local government offices to apply for a job.

Tabel 5 shows the data related to mother employment

Mother employment	Nr. of cases	Percentage (%)
Unemployed	12	70
Not living	3	18
invalids	1	6
Abroad	1	6
Total	17	100

From the data of Table 5 we can see that 70% of mothers are unemployed, so there is no personal income. Three of the mothers have died because of AIDS, one of them is disabled and therefore benefits KEMP of 12000 ALL, 1 case of working abroad and recently has taken away her HIV positive child.

One of the respondents (the mother of HIV positive child) said: "I would like to work but cannot since nobody can take care for my sick child."

Tabel 6 shows the data related to father employment

Father Employment	Nr. of cases	Percentage (%)
Unemployed	9	52
Not living	5	30
invalids	2	12
Works in private sector	1	6
Total	17	100

** *three children belong to the same family.*

The data above shows that 52% of HIV positive children's fathers are unemployed, 30% do not live (a case is murder and not death from AIDS), 1 case is self-employed, 1 works as a pizza delivery and a case works in construction. One of the fathers, who is currently unemployed, before diagnosis of the daughter with HIV positive worked in immigration. The mother cannot come alone with the daughter in Tirana, to perform the routine visits, so the father had to give up immigration and became part of the unemployed community.

Even those who have a job are only able to ensure the minimum income for their families, so when they are asked they could not give a figure for monthly income.

Regarding the parent's education we can say that 11 or 64% of them have elementary education, 5 or 29% have secondary education and only 1 case, which is the mother of three infected children, has higher education.

Regarding the education of the father we can say that 47% have primary education, 8 or 47% have secondary education and 1 case

who is the father of three children infected with HIV / AIDS has a university degree.

Regarding the residence we can say that: 12 children or 63% of them live in the countryside (3 of them in very remote areas), 6 or 32% in the city and a single case has moved recently abroad, 6 cases live in Tirana, and the rest in other regions of the country.

The taking care service of HIV positive children is centralized at the paediatrician section of the University Hospital Centre, so these children have to come at least once a month, to perform the next visit to infections-paediatrician. So far none of these children and their companions have received reimbursement for **transportation costs** despite the fact that this is a right based on Law No. 9952, of 7.14.2008, Article 8, paragraph e.

Rural life of course adds difficulties to their lives as here they cannot find all necessary facilities for a normal life, we can mention here the lack of high school which was a reason why a HIV positive child could not attend secondary education, or we could mention the fact that there are no possibilities of employment for the parents of these children in order to provide a better life.

Some of these children simultaneously suffer from health problems. We can mention here thalassemic children who have received the infection from blood transfusion. One of these children also received another infection, that of Hepatitis B through blood, so we can say that this child suffers from three serious health problems. The parent of this child raises rightfully the concern: ***"Should this case be differentiated? Do I need to get an extra social assistance for other problems obtained in Health Institutions?"***

Being in contact with the difficult economic situation of these families, the monthly income per capita and a number of other data, it is understandable that KEMP these children should receive can be a great help for them. But only 12 or 63% of them receive this assistance, 4 or 21% did not receive as a result of stigma and

discrimination of the detection of their HIV positive status, although in difficult economic condition runs in 2 of these cases,

1 case does not take it because the orphan child lives in a far away zone and relatives have neglected to bring him for medical treatment, jeopardizing her life,

1 case was moved abroad. It should be noted that most of the respondents felt that this help (KEMP) does not afford the numerous costs these children have, such as medicines for treatment of IO, the transportation costs for the next visits, etc..

Related to the monthly income per capita it is estimated that:

32% of the families of these children have the monthly income per capita from 5000-10000 ALL,

5% have monthly income per capita about 3000-5000 ,

21% have monthly income per capita 1000-3000,

10% had less than 1000 ALL.

For 32% of these families this figure couldn't be calculated

While in relation with the distance from Tirana, where children with HIV / AIDS are treated, it results that:

21% of these children currently live in a distance of more than 200 km from Tirana,

11% of them live in a distance of 125 km from Tirana,

16% of them in a distance of 80 km,

11% live in a distance of 40 km from Tirana and others living in Tirana.

Given the distance where the children with HIV / AIDS are living clearly emerges the **need for shelters for people with HIV and their families,** a problem raised by the representatives of the Association of PLWHA. For this purpose, they have deposited a request in the Municipality of Tirana, for providing a shelter for families and people with HIV living in the districts and treated with

antiretroviral therapy, treatment for which they have come to Tirana. While there is the possibility of finding funds for the provision of this environment, in which can be employed and PLWHA can help other people with HIV in this shelter.

All the above mentioned facts testify once again the lack of social policies to help children infected with HIV / AIDS and their families.

8. Section 6: ORPHANS AND PERSONS INFECTED WITH HIV/AIDS

Losing parents at a young age is a tragedy, because the loss is associated with the lack of attention, care and love of other people, relatives or society. It affects psychologically, socially and economically the child.

But losing parents from HIV / AIDS is a greater trauma. They are abandoned twice, once by chance and the second time by the society. Being infected does not mean not having the childhood, toys and above all the care and love of human beings.

Loss of parents faces you with many threats and challenges, risks that are increasing with augmented incidence of AIDS. For this reason, the decision-making structures should plan intervention that is directly linked with HIV positive orphans, as well as their families and communities.

Out of 19 HIV positive children included in our study, 5 of them are orphans from one parent (4 have lost the father and one has lost the mother due to AIDS) while 2 others have lost both parents and now live with their relatives.

In one case, the child has lost her father in 2003 and at the end of 2006 lost her mother. She was 8 years old when she lost her mother, a loss that left traces in her psychological state. She often says: "Will I die like Mom?" Consequences of this trauma were seen immediately in her psychological state and in physical problems that appeared, like enuresis Nocturne. She lived in her uncle's family for about 3 years,

a period in which she faced stigmatization and discrimination within the family, which led her to escape and live in a remote mountainous area, very distant, in her aunt's family. There are some years that she has stopped the antiretroviral therapy, because her relatives say she is "good." This child has not benefited KEMP for the health problem she has, as her relatives were not aware of this fact.

The same scenario is shown even from the other case, who has lost both parents from AIDS, but fortunately, she has resumed the interrupted antiretroviral therapy for a long time.

9. Section 7: LEGISLATION AND THE RIGHTS

Two are the documents defining the rights of children infected with HIV.

1. Convention on Children Right.
2. The law on HIV / AIDS approved since 2000, reviewed and adopted in 2008

The Convention as an international document, defines the right to have a better health condition and to profit from facilities for the treatment of the disease, the right to education, the right for every child to have an adequate living standard for his physical, mental, spiritual, moral and social development and a number of other rights that every child should enjoy.

The second document is the Law "On the prevention of the spread of HIV / AIDS in the Republic of Albania" it was adopted by the Parliament in 2000. Its implementation in practice and relevant experience at home and abroad, highlighted the need for revision of this law.

Due to the rapidly changing needs, MSH and ISHP prepared and drafted a new law on HIV / AIDS in Albania, which was approved by the Parliament in July 2008.

The law defines the rights and duties of HIV positive people in general and in particular the rights of children infected with HIV / AIDS. For example, the right of education for HIV positive children, the right for social assistance benefits in cash or services and condemns stigma and discrimination against these children.

Health and health services (Article 24)

The Constitution stipulates in Article 55 the right of citizens to equally enjoy the state health care. Health service in Albania is regulated by Law no. 3766, of 17.12.1963 "On health care" that has undergone changes later by Law no. 7718, of 03.06.1993 and Law no. 7738, of 21.07.1993.

The law provides the organization of health services in various private and public institutions. Under the state law, health care provided through health education, control and prophylactic measures of general, specific and relevant institutions, diagnosis, treatment and rehabilitation of the patient, etc.

Article 8
Rights and obligations of persons living with HIV / AIDS:

1. People living with HIV / AIDS enjoy the following rights:

a) health care, drug treatment, or outpatient hospital care, free at public health institutions;
b) education at all levels of the education system, public or private;
c) employment, in accordance with the requirements of the job;
d) the confidentiality of infecting them with HIV / AIDS;
d) refusal of treatment and medical examination, when they are getting complete treatment for AIDS;
f) integration into the community and society;
e) free transportation to treatment and care centers;
h) other rights provided by this law and other applicable laws.

2. People living with HIV / AIDS have the following obligations:
   a) implementing measures for prevention and transmission of HIV to others;
   b) information on HIV positive test result to husband / wife or partner
   c) other obligations provided by this law and other applicable laws.

Article 40
Social assistance for people living with HIV/AIDS

1. Persons less than 18 years old infected with HIV/AIDS, benefit social assistance in cash or services, when they are unemployed.
2. The type and amount of social assistance, as well as criteria and procedures for their distribution are determined by the Council of Ministers.

Persons infected with HIV/AIDS

1. Persons infected with HIV/AIDS should be taken care by their families, health and social state institutions.
2. Children infected with HIV/AIDS, who are abandoned and those who have lost contact with their families or the ability to work, should be taken into care from state social service institutions (residential social care institutions) or private ones.
3. Non-profit organizations or any other types may raise residential institutions to take care of persons living with HIV / AIDS.

10. Section 8: COMMUNITY, LOCAL GOVERNANCE AND CIVIL SOCIETY

The community where these children with HIV / AIDS live in most cases is not aware of their HIV positive status. In those cases where this fact is known, the community's feedback has been very tough. It is sad to see that a whole community requires these children to leave school or preschool, because according to them, "this child poses a risk to others." This situation has occurred in Tirana, but it is being repeated in other districts.

It is a fact that the lack of information, fear of contagion with this disease can induce severe reactions from the community, but if key individuals or "leaders" of the community will work with the latter, then these situations can be overcome successfully, like it has been demonstrated in the cases mentioned above. Mothers of children infected through blood say: *"Every time the media talked about AIDS, I thought the disease was far away from us, when I learned that my child was infected with HIV, I thought I had it inside my house."*

A preschool educator said: *"There must be awareness from the community towards the problems of HIV / AIDS, because there is a misinformation regarding the route of transmission."*

Civil society also has a very important role in raising the awareness of the community to the problems of HIV / AIDS, reducing stigma and discrimination against HIV / AIDS, protection of the rights of

children with HIV. It is worth mentioning the hard work done by the Association of People living with HIV / AIDS, community of parents of children with HIV, the support that this association has given to these families in difficult times.

But you cannot find the same support from centers/units established for the protection of child rights, supported by the municipalities. The latter should fight even more to protect the rights of HIV positive children. The representatives of various NGOs themselves, in meetings conducted in the districts said that HIV positive children can be an active part of these associations when they have a certain age, to protect their rights, as described in the Convention of Children Rights and the Law on HIV / AIDS.

In the 2008 law, in Article 6 it is stated that "Local authorities should include in their activity taking measures and services in order to prevent and control HIV / AIDS."

It is a fact that these people didn't want to share their health problems with other people, being those representatives of Local Government, and this is due to the prejudices that exist.

Also representatives of the Local Government were not aware of the fact that there are infected people with HIV / AIDS in their district, especially children, but as we have introduced them with the situation they have unanimously expressed that they will cooperate with all structures to support these people.

Thus, in the meeting held in Fier with Local Government representatives they expressed their willingness to assist in training of an HIV positive child, what would help in her social integration, making her feel valuable for herself and the society.

For cases that have been recognized by local authorities, the respondents stated that they have not had any support from local government for their health problems. Social assistance these children receive is 8700 All, which is certainly a symbolic aid that cannot fulfill all the needs and problems of these children.

Local government has a very good cooperation with various non-profit organizations (NPOs) that may be suggested to help HIV positive children. It is worth mentioning that Vodafone Albania through a project has come to help these children, providing Internet in their homes, to be closer to information on their disease, but also with other information of interest for their age to fill the gaps created by isolation from social life.

11. Section 9: FINDINGS AND RECOMMENDATIONS

11.1 FINDINGS FROM CONVERSATIONS, INTERVIEWS WITH PARENTS, RELATIVES, CAREGIVERS OF CHILDREN INFECTED WITH HIV.

1. The reaction of the community is still quite hostile to children with HIV / AIDS by not accepting them, stigmatizing and isolating them.
2. Stigma has affected the family, sisters or brothers of children infected with HIV / AIDS despite the fact that they have not been infected with this virus.
3. 21% of these children despite the difficult conditions did not receive KEMP due to stigma and discrimination that they may face when the others know their positive HIV status. A case does not take it due to loss of attention and neglect of her relatives to the problem of child health, since she has lost both parents due to AIDS.
4. 52% of HIV positive children's fathers are unemployed, 30% do not live, 12% of them are self-employed, a case or 6% is employed in private enterprises.
5. The economic situation of families of these children is very low. Thus 32% of the families of these children have a monthly income per capita from 5000-10000 ALL, 5% have

monthly income per capita in 3000-5000 ALL values, 21% have monthly income per capita in 1000-3000 ALL while 10% had less than 1000 ALL, and for 32% of these families cannot calculate this figure by not having a job defined.

6. KEMP, 8700 ALL for these people is so low it does not solve the economic needs of these families.
7. The absence of a special center for the treatment of these children has brought the family wandering children living with HIV / AIDS.
8. None of these parents is reimbursed for transportation costs by local authorities in cases when coming in Tirana, to obtain treatment or to carry out routine visits.
9. None of these children receive free treatment for opportunistic infections (OI) associated with HIV infection.

11.2 MAJOR FINDINGS OF THE STUDY

1. 26% of children included in the study are stigmatized and discriminated because of HIV / AIDS, the rest has kept HIV status secret not becoming subject of stigma and discrimination.
2. 16% of these children have lost their mothers due to AIDS, a fact that makes them even more vulnerable to HIV / AIDS, while 32% of children included in the study lost their father due to AIDS, aggravating their socio-economic status. 2 of these children or 11% of them have lost both parents and now live with their relatives.
3. Related with the mother's employment it is shown that 70% of mothers were unemployed, 18% of them have died from AIDS, one of the mothers is invalid and therefore receives KEMP of 12000 ALL, 1 case of working abroad who recently has taken her HIV positive child with her.

4. 63% of children infected with HIV live in the countryside, adding to difficulties in access to specialized center for treatment, which is located near the Tirana University Hospital Center
5. 21% of these children currently live in a distance of more than 200 km from Tirana where specialized health services for children with HIV / AIDS can be found, 11% of them live in a distance of 125 km away from Tirana, 16% of them are in a distance of 80 km, 11% live in a distance of 40 km from Tirana and others in Tirana.
6. 3 of these children or 16% of them are aware of the health problem they have, a fact which has had a heavy emotional impact.
7. 16 of these children or 84% of them receive antiretroviral treatment at QSUT, 2 or 11% gave up from the therapy, while one case diagnosed in 2010 began the therapy, but unfortunately died the same year.
8. Housing is a problem that facing the families of children infected with HIV / AIDS, which aggravates their socio-economic situation.
9. Local authorities did not have any information about the circulation of HIV in the country and the problems of HIV / AIDS in the municipality, their county or municipality.
10. There is not a good community awareness about HIV / AIDS. The reaction of the community is still quite hostile towards children with HIV / AIDS by not accepting, stigmatizing and isolating them.
11. Task force for children at the local level has no knowledge about the role it should play on HIV / AIDS and especially for children infected, affected and at risk.
12. Health personnel in districts does not yet differentiate

universal prevention measures or other and wants to get informed about positive HIV status of patients affected by HIV / AIDS, calling this the only way of protection.

13. School is one of the best institutions for educating students, parents and the community for HIV / AIDS. That is why it is required a periodic training for teachers or social employees working in schools. School doctors work less and have no specific programs.
14. Health personnel doesn't apply regularly universal prevention measures, not only due to the absence of defensive tools, but also lack of education in this area and lack of basic standard practices in health institutions.
15. There are no preliminary guidelines regarding testing and counseling for children and adolescents.
16. There are no protocols and training national guidelines, care and attendance of children living with HIV.
17. There are no functional national protocols regarding taking care of children living with HIV
18. As a result of lack of coordination there are some inaccuracies in the budget calculation for antiretroviral treatment and is lacking a dedicated fund for appropriate treatment and care for children living with HIV
19. There is a lack of cooperation of the central structures of pediatric care and that of adults, with those local care structures.
20. There was a lack of attention from local government, various NGOs for problems of HIV positive children.
21. It is identified the failure of the law on HIV / AIDS and the need of making immediate and approval mechanisms and guidelines for its implementation, accompanied with related costs approved by the Ministry of Finance.

22. Lack of information regarding the medical personnel HIV/ AIDS is expressed in the low percentage of personnel tested for HIV.
23. There is a lack of programs to prevent HIV transmission from mother to child
24. Testing for HIV is still not very common as it must be in order to get together as many teenagers at counseling and testing centers (VCT) established in regions.
25. Media plays an important role in sensitizing the community which makes necessary its continuous training
26. In some cases families have preferred not to take KEMP due to identification. We should work in institutional terms to find a solution for these persons to receive an assistance without being identified as HIV positive persons.
27. Lack of a shelter for family members and people with HIV is another problem raised by the representatives of the PLWHA, for this purpose, they have deposited a request in the Municipality of Tirana, for providing a shelter for families and people with HIV, living in districts and treated with antiretroviral therapy, treatment for which they have come to Tirana. While there is the possibility of finding funds for the provision of this environment, in which can be employed and PLWHA help other people with HIV in this shelter.
28. It should be emphasized that these children need a special treatment that according to pediatric medical staff it should be offered by a special center. One like this lack, since there is not a special environment that may be available to children with HIV / AIDS. The absence of this center is often brought to people wandering.

11.3 RECOMMENDATIONS

1. Integrating HIV testing and counseling for pregnant women, in the basic package of antenatal care services.
2. Providing HIV testing and counseling for pregnant women free of charge in public and private institutions, at the advice of maternal and child health as well as maternity.
3. Creation of a National Program for Transmission' Prevention from Mother to child (NPTPMC) that will reduce the born of an HIV positive child from the mother infected with HIV.
4. Implementation of the National Strategy for the establishment of a national reference center for PKPTNF at the Maternity "Koco Gliozheni" in Tirana.
5. Development of a specific strategy for actions to be undertaken for the creation of National Program for Transmission Prevention from mother to child.
6. Psycho-social and financial support for children with HIV / AIDS and their families.
7. In cases where such persons do not receive economic assistance that they are entitled due to stigma and discrimination (as has happened in reality) it is necessary to find an opportunity for these people to receive this assistance. (for example by provision of this center in the prefecture that includes their area or by opening a bank account, making it possible not to be identified.)
8. Integration of HIV positive children, involvement in various NGOs, in order to be an important factor in the fight against HIV / AIDS. Also, it can be carried out professional training of these children through various professional courses through the cooperation with NGOs and local authorities in districts. In cases when they are unable to attend school

for health reasons or for other reasons, then they should be provided with homeschooling

9. The acknowledgement of HIV / AIDS law by all actors and its correct application. Accompanying the Law with financial tools and maybe even with a guide to facilitate its implementation.
10. Review the Law of ISKSH revision of reimbursable medicine list (taking free of charge the medicaments for treating Opportunistic Infections) for HIV positive children.
11. To be categorized cases when this infection is taken in hospital institutions, for example through blood. Before a blood transfusion to a child, parents should explain the window period and should explain the risk that this transfusion may cause.
12. Continuous training of health personnel (doctors, nurses etc.) on the problems of HIV / AIDS.
13. Continuous training of psychologists, social workers that work at health institutions or at schools, on the problems of HIV / AIDS.
14. Training of educators, teachers and all staff of educational institutions on issues of HIV / AIDS.
15. Working more with the community, in order to alleviate the stigma and discrimination of people with HIV / AIDS.
16. Training the Media on HIV / AIDS problems, in order not to cope with unpleasant situations that have deepened the stigma against people with HIV / AIDS. Extend awareness campaigns throughout the year and not only during the 1 December.
17. Strengthening cooperation between the University Hospital Center (infectious and pediatric services) and analog services in the districts that treat patients with HIV / AIDS.

18. Strengthening counseling and testing centers of HIV in the districts, review of protocols and standards of operation and to make these services much more efficient.
19. Encouraging local governments to implement social policies for employment of PLWHA.

PURPOSE:

The purpose of this evaluation is to contribute to the creation of a positive and supportive environment for children living with HIV / AIDS and their families, in cities where they live, through two main objectives:

- Creation and dissemination of data about the challenges and stigma that HIV-positive children and their families, are facing in local and national level.
- Facilitation of discussions at the local level, and development of a consensus plan that what can local authorities and communities do to improve the environment by ensuring that HIV positive children and families receive basic services like education, health, social, economic aid, etc.

ANNEXES

ANNEX 4.1

Elbasan, më 09/11/2011

1. Data on HIV/AIDS in Elbasan district.
2. Some data about families of HIV positive children in Elbasan District.
3. Summary of minutes -Elbasan

I. DATA ON HIV/AIDS IN ELBASAN DISTRICT.

Total:	**15**
Male	**10**
Female	**5**
Children	**2**
AIDS	**7**
Adult death from	**4**

Regarding ethnicity 2 cases belong to the Roma ethnicity.

Based on the continuous investigations, results that 4 cases are been infected from virus outside the country and 11 cases are been infected within the country. In 2008 in Elbasan was established the Volunteer Counselling and Testing Centre (VCT) at Public Health Directory, in order to play an important role in sensitizing and increase the number of tests in this district.

In the table below is given the distribution of cases in Elbasan according to the year of reporting:

Table 2.

DISTRIBUTION OF HIV CASES IN YEARS 1993-2010, IN ELBASAN DISTRICT

Years	'93	'94	'95	'96	'97	'98	'99	'00	'01	'02	'03	'04	'05	'06	'07	'08	'09	'10
Nr of cases Elbasan						1				1	1		2		4	3	3	

As we can see from the above table in the last years there is an increase on HIVpositive cases in Elbasan district.
Regarding the ways of transmission the majority of cases are infected through sexual behaviours 12 cases (1 case homo-bisexual) and 3 cases from transfusion of infected blood.

Table 3.
DISTRIBUTION OF CASES ACCORDING TO TRANSMISSION WAY

Way of transmission	Nr. of cases
Blood	3
Heterosexual	11
Homo-bisexual	1
Total	15

Table 4.
DISTRIBUTION OF CASES ACCORDING TO THE AGE OF EACH PERSON

Age in years	Nr. of cases	Percentage
2	1	6.7%
15	1	6.7%
22	1	6.7%
32	1	6.7%
35	2	13.3%
36	1	6.7%
37	2	13.3%
38	1	6.7%
39	1	6.7%
42	1	6.7%
43	1	6.7%
50	1	6.7%
71	1	6.7%
Total	15	100.0%

So as it can be seen from the table distribution by age, for Elbasan district varies from 2 to 71 years old, but it is clear that predominates the sexually active age (12 cases) 22-50 years old, a common element even with the epidemic profile of HIV/ AIDS in our country.

Regarding the referral of cases in the district of Elbasan, 6 cases were referred by clinics, 4 cases were diagnosed as a result of epidemiological tracking, 3 cases were referred by Centre of Blood Control and only 2 cases were diagnosed as volunteers.

II. SOME DATA ON FAMILIES OF HIV POSITIVE CHILDREN IN ELBASAN DISTRICT

HIV positive children in Elbasan district were diagnosed in the years 2005, 2007. The child diagnosed in 2005 was 15 years old at the time of diagnosis and the child who was diagnosed in 2007 was only 2 years old. In both cases the way of transmission is through blood transfusion.

Case of year 2005

Psychological aspect

.....A thalassemic child who goes abroad hoping to transplant a bone marrow and there she learns that is infected with HIV. She was only 15 years old when she got this terrible news from the Italian doctors. She experienced this situation with a very great stress and her father almost in a state of shock (his first reaction was very severe). This situation led to the child depression...

After 5 years the child has accepted this fact, it seems like she is having a normal life since she is a student in the second year of high school, but again stigma and discrimination does not allow her to share the secret with her best friends, being afraid that she would be abandoned by the social group.
This family has 6 children from age 15 to 29 years old. All of them have faced this situation with stress and remorse.

Financial- economical aspect

A family with low income: The father is self-employed, the mother is invalid. The health problems of the child, talasemia and HIV/AIDS have had a great financial impact in their family. The child benefits KEMP of 8700 ALL as talasemic, but she should come at least 3 times a month to take blood transfusion. The child is always accompanied by the father in these visits and all these have a high financial cost for this family. Living conditions can be considered normal.

How does the parent judge the health system?

In general the treatment was good, but the father says that he is afraid from negligence...
The fact that this child is even thalasemic and HIV positive makes them to be very rigorous with the visits appointments. In his opinion , doctors and nurses treat them good.

What should be changed according to the parent?

It should be change the financial treatment for persons living with HIV/AIDS. It need to be differentiated the treatment of thalasemics and these kind of cases should be treated for both the problems separately, in financial view.

Case of year 2007.

This case was diagnosed in 2007 as a result of epidemiological monitoring made by the Institute of Public Health in summer 2007. The child was only 2 years old when he was diagnosed with HIV.

Psychosocial aspect

This HIV positive child has been diagnosed by a true friend of the family members. Mother says, "Whenever was mentioned AIDS in Media I thought that this disease was so far away from my family and when I learned about my child's diagnosis, I was shocked to have it in my house"

I did not have information for this disease, but I knew that the opinion is negative.
In these days the mother is being informed about this disease and the situation is quite, while the father has still reactions. According to the mother, Stigma and discrimination are in high levels among our society, -"people are terrified from this disease"- said the mother.
Now the child is 5 years old, but he has faced the discrimination effect, because the parents of other children in the kindergarten, which he frequents, do not want this child to stay in contact with the others, so they asked the isolation of this child...

Financial-economical aspect

It is a family with low income, in difficult living conditions (apartment 1 +1), with 3 children 4-8 years old, with unemployed parents and the enormous need of caring for children.
In order to maintain the family the father goes continuously abroad, but even there he cannot generate as much incomes as needed to do the family union. Having no other solution, he spends some times in Albania and sometimes aboard. The child's health problem has exacerbated the economic situation of the family.
They have to come every month in Tirana and this is additional cost for them.

How does the parent judge the health system?

According to the mother she felt stigmatized by the medical staff. They complain on health services "I had to wait 5 hours to finish all the things. There are medical expenses that I have to pay and it is difficult for our family- says the mother"

What should be changed according to the parent?

- The health system should reimburse travel and medical expenses.
- Employment for family members of HIV positive children
- Avoiding meanders
- Increase the information in the media about HIV / AIDS.

Summary of minutes of meetings in Elbasan

1. Presentation from ISHP related to the epidemiological situation of HIV / AIDS in our country and the district of Elbasan in particular, about the progress of the counselling and voluntarily testing in Elbasan and in relation to media coverage of cases of HIV / AIDS belonging to the district of Elbasan.
2. Elbasan community has reacted in concrete situations related to HIV / AIDS and needs a wider awareness by health professionals for these problems.
3. Parents of HIV positive children said that the social aid (KEMPI) that benefit the HIV positive children should be given even after the age of 18s.
4. To increase economic aid for health problems acquired in health

institutions such as HIV, Hepatitis B in case of a thalassemic children; when it comes to thalassemic children was highlighted the problem of blood shortages, especially during the summer

5. Application of reimbursement for travel expenses for child and family member that accompany, according to HIV / AIDS law.
6. To provide psychosocial support for families of HIV positive children.
7. To have a better cooperation between government agencies and non government ones for the problems of HIV / AIDS.
8. Local government should be more sensitive toward the problems of HIV positive children.

ANNEX 4.2

KUKES, 15 November 2010

1. Report of Kukes District

1. Data on HIV/AIDS in Kukes prefecture.
2. Some data on families of HIV positive children in Kukes district.
3. Summary of minutes of meeting in Kukes.

I. DATA ON HIV/AIDS IN KUKES PREFECTURE

Total:	**8 cases**
Kukes	**4 cases**
Has	**3 cases**
Tropoje	**1 case**

** These cases belong to the prefecture of Kukes, the data show that there are other cases which result in place of birth in the prefecture, but some others are living in Tirana for several years.*

Male	**6 cases**
Female	**2 cases**
Children	**4 cases (1 Kukes, 2 in Has and 1 in Tropoje).**
Death from AIDS	**3 cases (2 children +1 adult)**

Distribution in year's shows that in this prefecture have been reported cases since the first years, explicitly in 1996, but there are some cases even in 2010.

More detailed information is shown in Table:

District	Distribution of cases according to the years			
KUKËS	1996	2004	2008	2009
HAS	1996	1997	2010	
TROPOJË	2006			

*** The case in Tropoja in the time of diagnostic has lived in Shkozet, Durres and just in September 2009 went in a village in Tropoja, after the death of his parents from AIDS.*

Table 3: Kukes District

Nr.	Year of reporting	Age in years	Gender	Way of transmission	Survival
1	1996	36 years	Male	Bisexual	Dead
2	**2004**	**8 years**	**Male**	**Blood**	**Alive**
3	2008	65 years	Male	Bisexual	Alive
4	2009	58 years	Male	Bisexual	Alive

Table 3 interpretation

The first case diagnosed in 1996 belonged to blood donors by blood banks, while other cases are referred from clinics in the AIDS stage.
4 cases were male and according to the years given in the table above belong to age 36 years, 8 years, 65 years and 58 years old.
Three adult cases belong to homo-bisexual way
1 case of a child who received this virus through blood transfusion at the age of 6 months; and was diagnosed at age of 8 years.
Case of 1996 was identified from the death. (Reason not because of AIDS)
Besides the 4 cases who live in this district there are two cases pertaining to homeland Kukes and in the time of diagnosis they lived in Tirana.
These cases have received this infection ***within the country.***

Table 4: Has district

Nr.	Year of reporting	Age in years	Gender	Way of transmission	Survival
1	1996	26 years	Female	Blood	Alive
2	1997	18 months	Male	Vertical	Dead
3	2008	15years	Male	Blood	Dead

Among three reported cases, 2 cases (cases reported respectively on 1997 and 2010) are children who belong to ages 18 months and 15 years.

Case of 1997 has taken this infection through vertical way and the case of year 2010 has taken this infection through blood. Both cases have died in the same year with that diagnosis.

Case of 1996 is an adult female and has received this infection through blood transfusion during the birth. This case lives and regularly receives antiretroviral therapy.
All three cases have received this infection within the country.

Tropoja District:

The case that is currently living in Tropoja is a child of 12 years old, orphaned after both parents died of AIDS. She lives with her relatives in a village of Tropoja.

At the time of diagnosis she was only 8 years old, so she was diagnosed in 2006. Her father died in 2003, while the mother at the end of 2006.

It is a case that needs special attention, not forgetting her psychological trauma after losing both parents, but the fact that living in a remote area from Tirana, which has led to secede from antiretroviral therapy for more than one year.
If we refer to the place of birth (Tropoja), there are included 4 other HIV positive cases in adult age groups respectively: 43, 42, 22 and 59 years old, diagnosed in the years 2005, 2005, 2009, 2009. The first two cases had the high education. These cases live in Tirana.

II. SOME DATA ON FAMILIES OF HIV POSITIVE CHILDREN IN KUKES DISTRICT

HIV positive children of the district of Kukes and Has have been diagnosed respectively in 1997, 2004 and 2010.
These three cases are infected through the blood transmission, cases between 2004 and 2010 received direct transfusions, and the child of 1997 is infected by vertical transmission from mother who had received blood transfusion during the process of giving birth of the child.
From epidemiological investigation results that the case identified in 2004 was infected in 1996, period in which we have diagnosed the first case of blood donator in this district.
We can say the same thing for the case of woman from Has that has been infected in 1996.
Case of 2010, 15 years old from Has, is been diagnosed in 2010 and has come under different transfusion of blood products in the hospital of Kukes or Tirana.

Case of 2004.

Psychological aspect

... Child diagnosed at age of 8 years. He has spent part of his life in different hospitals. The disease has made him depressed and he does not tell the thing to friends. He has started to understand the health problem and this is shown in his interest for the hospitals. He goes to school regularly.

Economic- financial aspect

He lives in a family with low income with unemployed parents.
Health problems of the child have had a great financial impact in this family with 5 children, respectively of age: 29, 27, 23,15 and 13 years old.
The child benefits economic assistance of 8700 ALL but should come at least once a month in Tirana, to take the medication for the upcoming month also for the routine controls.
The child in these visits is accompanied by the father or the older brother and all these travel expenses are financial costs for this family. They live in difficult conditions.
The travel from his house to Tirana is really expensive, and as consequence he does not take the antiretroviral therapy regularly, affected in this way in having different health problems..

How does the parent judge the health system?

The father has complains for health system, these complaints have histories dating back to 1996, when doctors decided that his child should received a blood transfusion and continuing..

What should be changed according to the parent?

There's nothing they can do to change the damage caused to his child according to the parent, while according to the brother there are some suggestions listed below:

- Should be reimbursed travel and medical expenses.
- Employment for family members of HIV positive children.
- Avoiding of meanders

2. Minutes of Kukes meeting.

In the district of Kukes issues related to HIV / AIDS was focused on the following points:

1. Lack of information about the situation of HIV / AIDS in this Prefecture. Was appreciated the initiatives taken by PHI to reflect the situation of HIV / AIDS in this Prefecture and the invitation made at this meeting for many actors (local rulers, specialists of HII, Public social services, doctors, teachers, families of children HIV positive).

2. Kukes Prefecture is an area of outstanding border for immigration, so it needs to be working hard towards the prevention of HIV / AIDS.
3. The different strategies adopted, the laws should be accompanied by funding that facilitates their implementation. Now it's time to come up with concrete proposals, in institutional ways on how to help HIV positive persons
4. In the book of HII, AIDS is not introduced as a separate category, so through the suggestions of specialists of HII the pharmacists had violated the law helping HIV positive persons. For other medical problems associated with HIV positive persons that require antibiotics, antimycotic etc. often becomes a violation of the law.
5. There is a lukewarm cooperation between the MoH and HII.
6. There is a clinic file for pregnant a woman which is not implemented. It would be important to carry out testing for HIV for pregnant women; Hepatitis B, especially for the first child, the benefit would be great.
7. Doctors must be aware of HIV status of the patient
8. School is the best place that can serve as points for awareness of population as it provides a large part of the community, pupils and parents. But the teacher should know HIV status of the student. Themes developed in the ninth grade would probably be better to place the doctors rather than teachers.
9. Teachers should be trained on universal prevention measures
10. Economic assistance that HIV positive persons receive is "ridiculous ", in some cases had to be hospitalization of these people in order to get proper treatment because they themselves do not handle this.
11. When the infection is taken in hospital institutions, so through blood transfusion, should be categorized. Before a blood transfusion to a child, should be the explanation to the parent about the window period and to be aware about the risk that this transfusion can bring.
12. Law of HIV / AIDS should be implemented; the Law of HII should be revised.

ANNEX 4.3

Vlora, 23/11/2010

1. Report of Vlora District:

1. Data on HIV/AIDS in the District of Vlora.
2. Some data on child with HIV positive in Vlora
3. Summary of minutes of meeting in Vlora.

I. DATA ON HIV / AIDS IN VLORA.

Total:	**16 cases with HIV positive.**
Men:	**12 men**
Female:	**4 females**
Child	**1**
AIDS	**4**
Persons dead from AIDS	**4 (3 adults +1 child)**

In the following table is shown the distribution by years of HIV+ cases in the district of Vlora.

Table 2.
DISTRIBUTION OF HIV CASES IN YEARS IN THE DISTRICT OF VLORA 1993 - 2010

Years	'93	'94	'95	'96	'97	'98	'99	'00	'01	'02	'03	'04	'05	'06	'07	'08	'09	'10
Nr of cases Elbasan		2						1		1	1				6	2		3

Table 3.
DISTRIBUTION OF THE HIV/AIDS CASES BY AGE, FOR THE DISTRICT OF VLORA

Age	No.Cases	Percentage
4 months	1	7.1%
18	1	7.1%
20	1	7.1%
23	2	14.3%
24	1	7.1%

Age	No.Cases	Percentage
28	1	7.1%
29	1	7.1%
30	2	14.3%
32	1	7.1%
35	1	7.1%
36	1	7.1%
49	1	7.1%
Total	14	100.0%

** For 2 cases the data are missing*

Table 4.
DISTRIBUTION OF HIV/AIDS CASES BY RESIDENCE IN THE DISTRICT OF VLORA

Residence	Nr. of cases
village	3
city	13
Total	16

Table 5.
DISTRIBUTION OF HIV/AIDS CASES OF THE DISTRICT OF VLORA BY SURVIVAL

Survival	Nr. Of Cases
live	12
dead	4
Total	16

Table 6.
DISTRIBUTION OF HIV/AIDS CASES OF THE DISTRICT OF VLORA BY REFERENCE

Reference	Nr. of Cases
Clinics	8
Epidemiological monitoring	1
QKTGJ	1
Volunteer	6
Total	16

Table 7.
DISTRIBUTION OF HIV/AIDS CASES OF THE DISTRICT OF VLORA BY THE WAY OF THE TRANSMISSION

Way of transmission	No. of Cases
Heterosexual	14
Homo-bisexual	1
Vertical	1
Total	16

Table 8.
DISTRIBUTION OF THE CASES HIV/AIDS IN THE DISTRICT OF VLORA BY STAGE

Stage	No. Of Cases
AIDS	4
HIV	12
Total	16

Regarding the marital status at the time of diagnostic, 4 of them are **married (2 couples)** and they are desintosicated in couples, one case is **divorced**, one case is **child** and the rest are singles.

Some data on HIV positive children

The HIV positive child of the District of Vlora was diagnosed at age of 4-months-old, in 2007.
He was referred as clinic case. In this family three members were infected: mother, father and the child.
The route of transmission was vertical from the mother to the child.
HIV / AIDS became a cause of the death of this child. Her parents are alive and they are living in Italy as emigrants.

3. Summary of minutes of meeting in Vlora

Problems and suggestions in the meeting in Vlora

- There must be a greater awareness of the community of adolescents about the location of the VCT in Vlora' District.
- The success in preventing HIV / AIDS will be achieved through the commitment of each stakeholder in the field of prevention.

- HIV/AIDS issues must be persistent part of medical staff qualifications.
- The information on the situation of HIV / AIDS it must be on a regular basis.
- The law puts health staff ahead of his obligations. The law must be known by each level of medical staff.
- The epidemiological service should be informed
- There must be a connection between the Center and Base, then have a close collaboration between PHD in region and pediatric service in terms of recognition of the Law
- Is decreased the age of first intercourse; in 25 cases tested for STI 25% are Chlamydia. It is necessary to work more with the groups of young people
- Stigma and discrimination are in high level even among medical staff which is reflected also at the percentage of this staff tested for HIV.
- The women's advisory centre is a very good place for testing of young people groups.
- Law of 2008 is precise but MoH should have placed specific disposes for this law implementation. There is no instruction for this law implementation.
- There is a neglect of the community and civil society towards the problematic of HIV / AIDS.
- The level of stigma is high; there is stigma to carry out the testing for HIV.
- The place where testing is performed is very important, this test should be so friendly. In the hospital is not performed the testing for HIV.
- There should be more training for HIV / AIDS and IST

ANNEX 4.4

Durrës, 14/12/2010

Contents of this information:

1. Data on infected children, District of Durres.
2. Summary of minutes of meeting Durres.

I. DATA ON HIV / AIDS IN THE DISTRICT OF DURRESIT.

Total:	**23 cases HIV positive.**
Male:	**13 men**
Female:	**10 female**
Children	**3 cases**
Deaths	**3 cases**

In the following table is shown the distribution by years of HIV+ cases in the District of Durres.

Table 2.
DISTRIBUTION FOR HIV CASES IN YEARS IN THE DISTRICT OF DURRES1993 – 2010

Years	'93	'94	'95	'96	'97	'98	'99	'00	'01	'02	'03	'04	'05	'06	'07	'08	'09	'10
Nr of cases Durres			2							4	1	2		2	2	1	8	1

Tabela 3.
DISTRIBUTION OF THE HIV/AIDS CASES BY AGE- DISTRICT OF DURRES

AGE	No. Cases	Percentage
1	2	8.7%
8	1	4.3%
21	1	4.3%
24	2	8.7%
25	1	4.3%
26	1	4.3%
27	1	4.3%
28	1	4.3%

AGE	No. Cases	Percentage
31	1	4.3%
32	1	4.3%
33	2	8.7%
37	2	8.7%
39	1	4.3%
40	1	4.3%
41	1	4.3%
46	1	4.3%
48	1	4.3%
49	1	4.3%
50	1	4.3%
Total	23	100.0%

Table 4.
DISTRIBUTION OF HIV/AIDS CASES IN THE DISTRICT OF DURRES BY RESIDENCE

Residence	No. Cases
village	3
city	20
Total	21

Table 5.
DISTRIBUTION OF HIV/AIDS CASES OF THE DISTRICT OF DURRES BY SURVIVIAL.

Survival	No. Cases
live	20
death	3
Total	23

Table 6.
DISTRIBUTION OF HIV/AIDS CASES OF THE DISTRICT OF DURRES BY REFERENCE

Reference	No. Cases
clinics	9
epidemiological monitoring	5
QKTGJ	6
volunteer	3
Total	23

Table 7.
DISTRIBUTION OF HIV/AIDS CASES OF THE DISTRICT OF DURRES BY THE WAY OF THE TRANSMISSION.

Way of the transmission	No. Cases
heterosexual	18
homo-bisexual	2
vertical	3
Total	23

Table 8.
DISTRIBUTION OF THE CASES HIV/AIDS IN THE DISTRICT OF DURRES BY STAGE

Stage	No.Cases
AIDS	4
HIV	19
Total	23

2. SOME DATA ON HIV POSITIVE CHILDREN:

There are diagnosed 2 cases of HIV positive children in the District of Durres at 1 year old, respectively in 2002 and 2007, and the third case diagnosed in 2006 at the age of 8 years old. In the three cases the way of transmission was vertical one.

The case of 2002 belonged to the orphanage in Durres,

The case of 2006 was diagnosed after the diagnosis of the mother (father at that moment was died because of AIDS).

The case of 2007 was initially diagnosed abroad, in Austria and after a series of meanders in health institutions in our country.

The three cases of Durres appeared with many social and economic problems;

The case of 2002 belonged to the orphanage of Durres.

The case of 2006 is an orphan that lost both parents because of AIDS.

The case of 2007 is a child of divorced parents.

3. SUMMARY OF MINUTES OF MEETING IN DURRES

The meeting was opened with the presentation of ISHP specialist about the situation of HIV / AIDS in Albania, and mainly of the children, and the situation in the District of Durres.

Then the discussion was focused on the psychosocial and economic needs

of the children with HIV / AIDS. These are some of the participants' concerns, opinions and recommendations:

- The doctor and the teacher should be informed about the status of HIV positive children, despite the fact that the doctors are told to treat every patient as if they had HIV.
- There is lack of the kits; there is a lack of gloves, and other infrastructure problems. The equipment with device ELISA requires the training of the personnel.
- There must be a national program for prevention of HIV from mother to child.
- All staff members that work in the room must do the testing for HIV because they are very vulnerable working without protective measures and where accidents occurred. The percentage of the staff tested is very low.
- There is no association that deal with children living with HIV / AIDS as it has for children in need. Should be made also the promotion of VCT center.
- The doctor of family should play an important role in sensitizing the community.
- The doctors of family should work more, they should be trained and not only the doctors of the family. They will know how will behave with the parents, with the children when they will grow up, and to know the law better.
- Related to the collaboration needed in the field of prevention, there must be joint projects and activities between the Regional Educational Directorate, that is located in the District, in collaboration with the Media.

ANNEX 4.5

Rrëshen, 10.12.2010

Contents of this information:

1. Data about HIV/AIDS in the District of Mirdita.
2. Summary of minutes of meeting in Rreshen, 10.12.2010

I. DATA ON HIV / AIDS IN THE DISTRICT OF MIRDITA

In the District of Mirdita there are reported three cases of infected with HIV, which are members of a family, so both parents and their child. At the time of diagnosis both of the parents were 29 years old and their child was 1 year old.

They were reported in 2009, and they live together with other members of the family, who are not aware of their health problem, this because of the stigma and discrimination.

All three members are referred to University Hospital Centre (hospital infectious and paediatrics) and receive the antiretroviral therapy. Because of the risk of their identification in community, they do not get KEMP of the child.

Summary of minutes of meeting in Rreshen, (concerns, opinions and recommendations)

1. Awareness of the medical staff or other providers of the health services about the problems on HIV / AIDS and the treatment of the infected persons with HIV, as all other persons, is needed.

2. It must be known the positive HIV status of the person to the doctors who treat directly the person HIV-infected and to the teachers who educate these children in order to protect her/him and other children.
3. The teachers and the educators should be trained. There are been involved in the scholastic curricula themes on HIV, but such issues should be discussed continuously throughout the year.
4. It must be suggested to the Ministry of Health to come up with a directive that the entire population should be subjected to general analysis once in a year, in order to identify new possible cases.
5. In order to keep the anonymity and in the same time to obtain the KEMP, it is better that KEMP to be provided in the Prefecture and not in Municipality or Local Authorities, where infected children with HIV are living.
6. Active involvement of the psychologist for the families of the children HIV positive.
7. The Law of HIV / AIDS should be known not only by service providers, but also by all members of the communities
8. Improvement of the infrastructure of health institutions and the implementation of universal prevention measures.

ANNEX 4.6

Tirana, 16-02-2011

TABLE OF CONTENTS OF THIS MATERIAL:

I. DATA ON HIV/AIDS IN TIRANA DISTRICT.

In Tirana are reported 212 cases or 52% of the total cases. The table below shows the distribution of cases according to the years.

Years	'93	'94	'95	'96	'97	'98	'99	'00	'01	'02	'03	'04	'05	'06	'07	'08	'09	'10
Nr of cases Tirana	2	3	5	6	1	2	4	3	12	14	14	14	19	12	20	33	31	18

These cases are resident in Tirana, but in terms of place of birth 21 of them were born and grown up in other districts of the country and only recently they have came to live in Tirana.

The table below shows the cases according to the gender:

Gender	Nr. of Cases	Percentage
Female	63	29.7%
Male	149	70.3%
Total	212	100.0%

Related the surviving of these cases, 44 of them died from AIDS.

The most affected group age is 25-45 years that highlights the fact that in our country is predominantly sexual route of transmission of HIV / AIDS since the affected age group is sexually active.

Route of transmission	Nr. of cases
Blood	2
Heterosexual	182
Homo-bisexual	19
Drug users	3
Vertical	6
Total	212

Data on the education of these people are for 126 cases in Tirana district, and the table below clearly indicates that the majority of them have secondary education and there are some with higher education.

Education	Nr. of cases	Percentage
Preliminary school	29	23.0%
University	21	16.7%
High school	73	57.9%
No education	3	2.4%
Total	126	100.0%

The table below shows the reference of these persons:

Confession	Nr. of cases
Clinics	141
American lottery	1
Epidemiological monitoring	19
QKTGJ	19
Volunteer	31
Total	212

It is clearly indicated that very few of them are voluntarily tested, 31 cases or 15% of the total cases of Tirana, which highlights again that the voluntary testing and counselling service should be strengthened. The table below indicates the marital status at the time of diagnosis, in which are given data for 129 cases in Tirana district.

Marital status at the time of diagnosis	Nr. of cases	percentage
Single	35	27.1%
Divorced	6	4.7%
Married	88	68.2%
Total	129	100.0%

Regarding the place of taking the infection (according to what cases say) there are data for 149 cases and they are as follow:

Place in which have been infected	Nr. of cases	Percentage
Within the country	98	65.8%
Abroad	51	34.2%
Total	149	100.0%

As you can depict from the above table the majority of cases or 66% think that they are infected within the country.

II. SOME DATA ON INFECTED CHILDREN IN TIRANA DISTRICT.

In Tirana were diagnosed 6 children with HIV / AIDS.

The 6-infected cases with HIV in vertical transmission received from mother to child, so this mean that are infected their parents as well.

4 out of these children (where 3 of them belong to the same family) have lost their fathers, because of AIDS and nowadays they live with their infected mothers.

Age of these children is: 15 years old, 10.5 years, 9 years (2 cases), 3 years and 1 year old.

The last 2 children live with both parents who are infected with HIV/AIDS and in difficult living conditions, while the other parts have more adequate living conditions.

The moment of their diagnosis has been a trauma for them. Three of these cases are discriminated by not being allowed to frequent the kindergarten (the case that is now 3 years old) and two cases (of age 9) have had problems to attend schools.

These problems are been solved in close collaboration of MoH, MoE and Public Health Institute' specialists. 5 of these children take the antiretroviral therapy, while for one this therapy it is not needed.

The summary of recommendations during the meeting in Tirana
16-02-2011

- Every educational institution should have information on universal prevention measures.
- It is necessary the information, education and training of the media on HIV and all issues related to it.
- Offering of IEC (Information, education, communication) of all society on HIV / AIDS continuously.
- Implementation of the law and increase of its effectiveness toward the PLWHA rights and needs.
- Better recognition and enforcement of law by all institutions.
- The increase of role of school as an important educational institution in information and on improvement the knowledge on HIV/AIDS prevention and in reducing the stigma and discrimination toward PLWHA.
- Support and financial aid from the governance for PLWHA.
- Redesigning the regulation of the Ministry of Health on HIV/AIDS matters.
- It is necessary a better communication and inter-institutional collaboration,
- More efforts must be put on the Prevention of transmission from mother to child.

ANNEX 4.7

Fier

CONTENTS OF THIS MATERIAL:

I. Data on HIV/AIDS for the District of Fier.
II. Data on infected children that belong to the District of Fier.
III. Summary of minutes of meeting in Fier.

I. DATA ON HIV / AIDS IN THE DISTRICT OF FIER.

In the District of Fier there are reported 13 infected cases of HIV/AIDS. In the table below is given the distribution of cases by years.

Years	'93	'94	'95	'96	'97	'98	'99	'00	'01	'02	'03	'04	'05	'06	'07	'08	'09	'10
Nr of cases Fier								1			2	1	3	3	1		2	

As above mentioned the data in Fier are been reported after the year 2000. Regarding the gender 8 of them are males and 5 of them are women, 5 of them are married, one is widow and the rest are singles.

Gender	No.Cases	Percentuage
Female	5	38.5%
Men	8	61.5%
Total	13	100.0%

Related to their survival 4 of 13 cases have died because of AIDS.
The way of transmission is given in the table below, 2 cases that have received this infection through blood are children diagnosed in 2005 respectively at ages 5 years and 14 years old.

Way of the transmission	No. Cases
blood	2
heterosexual	9
homo-bisexual	1
Drug users	1
vertical	0
Total	13

Related to the education level, there are data for 12 persons only (which are mentioned in the table below), meanwhile this data for 1 case is missing.

Education	No. Cases	Percentage
Primary school	6	50.0%
High school	5	41.7%
Without education	1	8.3%
Total	12	100.0%

Related to the age of these cases, see this Table.

Age	No. Cases	Percentage
5	1	7.7%
14	1	7.7%
22	1	7.7%
26	2	15.4%
29	1	7.7%
37	1	7.7%
39	1	7.7%
41	1	7.7%
45	1	7.7%
47	2	15.4%
60	1	7.7%
Total	13	100.0%

Related to the reference of these persons is given the following table:

Reference	No. Cases
Clinics	7
American Lottery	1
Epidemiological monitoring	2
Volunteer	3
Total	13

Even in Fier there are only 3 cases identified voluntarily, which means that VCT services should be strengthen. Most of the cases are been referred by the clinic, a fact that stresses that the persons come and been diagnosed at an advanced stage.

Related to the place where they have received the infection (according to what the cases specifically refer) the data are as follows:

Place of received infection	No. Cases	Percentage
In the country	9	69 %
Abroad	4	31 %
Total	13	100.0%

*** There are been reported 2 HIV/AIDS cases in Mallakaster.*

II. DATA ON THE INFECTED CHILDREN THAT BELONG TO THE DISTRICT OF FIER.

There are diagnosed 2 children with HIV / AIDS in Fier

The way of transmission for the both two cases is through the blood transfusion, since teh two children are thalassemic and are been diagnosed in 2005.

Their actual age is 20 years old and 10 years old.

Their families have experiences trauma in the moment of their diagnosis. The person of age 20 years old is aware of her HIV status, which has derived her in to depression and the only two people she spoke with are her mother and the family's doctor. This girls wasn't able to finish the high school, because there is no high school in the village where she lives in. She has finished by herself the primary school, because she is very intelligent. She lives with 6 members of the family, including the uncle who is mentally disabled.

The other child (10 years old) has failed to perform even the primary school, because of health problems, is quite weak.

Besides their economic daily problems, they have to face the expenses of travel from their place of live to Lushnja (2 times per month), in order to get blood transfusions and the medical treatment (antiretroviral) 1 time per month in Tirana, accompanied by parents.

III. SUMMARY OF MINUTES OF MEETING IN FIER.

Suggestions and recommendations issued from the meeting of Fier

- Because of the fact that is impossible for these children to follow the schools the Education Directorate in the District of Fier should be in charge to offer them individual education, so to offer education to the children in their place of living, respecting in the same time the anonymity of their problems.
- Since the District of Fier has many thalassemic cases, the attention must be increased toward the group that makes blood transfusion regularly.

- The services of VCT should be strengthened and it needed to work more in terms of awareness of the population for the HIV / AIDS.
- Another group at risk that live in Fier district is Roma community, which means that it is necessary a better cooperation between specialists of Public Health Directory of Fier and these communities members.
- The District of Mallakaster who belongs to this local administration is consists of a community with a prejudiced mentality, so it would be better to organize a meeting in this district.
- All the interested institutions should work better with the pregnant women in order to increase the number of tests in this group.
- The case of the young of 20 years old, which is out of attention, would be better to be involved in another NPOs activities, in order to be integrated in the society, such as professional courses.
- In Fier are not been made emotransfution of the thalassemic anymore:
- The doctor's family that follow the case of the child HIV positive admit that:
  - The family need economic help to cover the travel expenses
  - They face many problems with the insurance of the medicaments that are not including in the lists.
- The responsible persons and institutions should discuss on the list of reimbursable drugs for involving the appropriate ones for PLWHA and especially for CLWHA.
- The financial support should be regulate by the Law (provisions)
- The Media should play an important role in sensitizing the community related to HIV/AIDS issues.

ANNEX 4.8

Lushnje

Contents of this information:

1. Data on HIV/AIDS in the District of Lushnja.
2. Some data on families of HIV positive children.
3. Summary of minutes of meeting in Lushnje.

I. DATA ON HIV / AIDS IN THE DISTRICT OF LUSHNJE.

Total:	**21cases HIV pozitiv.**
Men:	**13 men**
Female:	**8 female**
Children	**2 cases**
Deaths	**6 cases**

In the following table is shown the distribution by years of HIV+ cases in the district of Lushnja.

Table 2.
DISTRIBUTION FOR HIV CASES BY YEARS IN THE DISTRICT OF LUSHNJE 1993 – 2010

Years	'93	'94	'95	'96	'97	'98	'99	'00	'01	'02	'03	'04	'05	'06	'07	'08	'09	'10
Nr of cases Lushnje								3	1		1	2	3	7			1	3

Table 3.
DISTRIBUTION OF THE HIV/AIDS CASES BY AGE, FOR THE DISTRICT OF LUSHNJE

Age	No. Cases	Percentage
2	1	5.0%
8	1	5.0%
20	1	5.0%
25	1	5.0%
28	3	15.0%
29	1	5.0%
30	1	5.0%
32	1	5.0%

Age	No. Cases	Percentage
35	2	10.0%
37	1	5.0%
38	1	5.0%
40	1	5.0%
47	1	5.0%
48	1	5.0%
49	1	5.0%
54	1	5.0%
55	1	5.0%

Table 4.
DISTRIBUTION OF HIV/AIDS CASES BY RESIDENCE-DISTRICT OF LUSHNJE

Residence	No.Cases
village	11
city	10
Total	21

Table 5.
DISTRIBUTION OF HIV/AIDS CASES BY SURVIVAL-DISTRICT OF LUSHNJE

Survival	No. Cases
live	15
death	6
Total	21

Table 6.
DISTRIBUTION OF HIV/AIDS BY REFERENCE- DISTRICT OF LUSHNJE

Reference	No. Cases
clinics	17
epidemiological monitoring	2
volunteer	2
Total	21

Table 7.
DISTRIBUTION OF HIV/AIDS BY THE WAY OF THE TRANSMISSION-DISTRICT OF LUSHNJE

Way of the transmission	No. Cases
heterosexual	15
homo-bisexual	4
vertical	2
Total	21

Table 8.
DISTRIBUTION OF THE HIV/AIDS CASES BY STAGE-DISTRICT OF LUSHNJE

Stage	No. Cases
AIDS	6
HIV	15
Total	21

Some data on HIV positive children in Lushnja district

HIV positive children of the District of Lushnje are diagnosed in 2006. They live in two villages of Lushnja.

One of these children lives with the uncle's family since the parents have died from AIDS.

The other case lives with the two parents who are HIV positive as well.

Besides the fact that the families of both two children lives in difficult living conditions, the other huge problem for them is stigma and discrimination, which has affected these families the most.

3. SUMMARY OF CONCERNS AND RECOMMENDATIONS DURING THE MEETING IN LUSHNJE.

- According to the participants, the weakness point of Lushnja's District is the lack of information. They do not have full information for this phenomenon so the material of education are necessary for all the related institutions in order to better know this problem and offering professional aid.
- It is necessary the offering of training sessions for all stakeholders involved on prevention, education and treatment of PLWHA.

- The teachers and the educators in kindergarten should be aware of the fact if a child is infected with HIV.
- Ongoing cooperation of all structures for the problems for the HIV / AIDS.
- Should be more towards the counselling process and advisory of the mother and the child; towards the awareness and on the condom distribution, leaflets, posters on STI, HIV, etc. mainly for the young people.
- Increased awareness among pregnant women will impact directly on the reducing of the number of births of children with HIV, in terms of MTCT.
- Training of psychologists of DFS's and also of the schools.
- One suggestion is that perhaps it might be used the testing process when people goes to determine the blood group for the driving license, in order to identify new cases with HIV.
- The local government should be more attentive to the cases with HIV / AIDS.
- Better collaboration between health and educational institutions is needed.
- It is necessary the updating of the knowledge of the teaching staff about HIV / AIDS and about the legislation for this issue.

ANNEX 4.9

Dibër

CONTENT OF THIS MATERIAL:

I. Data on HIV/AIDS for Dibra prefecture.
II. Some data on infected children in Dibra district.
III. Summary of minutes of meeting in Dibra.

I. DATA ON HIV/AIDS FOR DIBRA PREFECTURE.

In Diber are reported 4 cases infected with HIV/AIDS, 2 in Mat and 1 in Bulqize, so in total there are 7 cases.

Their distribution according to years is given in the following table:

Years	'93	'94	'95	'96	'97	'98	'99	'00	'01	'02	'03	'04	'05	'06	'07	'08	'09	'10
Nr of cases Diber								1	1				1	1		1		1

Gender	No. of cases	Percentage
Female	2	
Male	5	
Total	7	100.0%

The way of transmission is shown in the table below, 6 cases have been affected by this infection heterosexually while 1 case through vertical way, so from infected mother to the child.

Way of transmission	No. of cases
Blood	0
Heterosexual	6
homo-bisexual	0
Drugs users	0
Vertical	1
Total	7

Data for the education level of these persons exist for 5 cases that belong to Dibra prefecture: 3 have the primary education, 3 high schools, and one is a 10 years child. Three cases of Dibra district live in village while the other cases live in the city.

Related to the age of this cases in the other table is given the age of every case;

Age	No. of cases
4 years	1
20 years	1
30 years	1
37 years	1
40 years	1
42 years	1
71 years	1

Based on the confession of these people all the information related to the place of identification, are indicated in the below table:

Confession	No. cases
Clinics	4
Epidemiological monitoring	1
BKTGJ	2
Total	7

So it is clearly indicated that no one has been tested voluntary, what highlights again that the testing and counselling voluntarily should be strengthened. The majority parts have confessed at clinics, fact that they are diagnosed in an advanced stage.

Place of taking the infection	No. of cases
In the country	5
Abroad	2
Total	7

II. DATA ON THE INFECTED CHILD IN DIBRA DISTRICT

In the district of Dibra the only case of child infected with HIV has received this infection through vertical rout. Actual age is 10 years old. He lives in a mountain village of Dibra district.

In his family are two persons infected; the child and his mother.

Stigma and discrimination have reached so far within this family that is affecting in the deep poorness; the family do not get the economic assistance provided to children in this case (8200 ALL) because the child and the family will be identify within the community. In the same way they have to ensure the expenses for travel, because the child accompanied by parents must travel every month in Tirana for antiretroviral treatment.

III. SUMMARY OF MINUTES OF MEETING IN DIBER

1- As members of this society PLWHIV have their rights and they should not be stigmatized and even more children. They should be integrated to have access to all services.
2- Another problem on our health services provided is sterility of tools or kits, for example it should be asked to the dentist for sanitary regulations, and it is needed to sensitize the population about protective measures.
3- According to the law, institutions beside the awareness for prevention should help PLWHIV. Municipality gives economic aid to invalids or disable persons such as paraplegics, but have no law for PLWHIV. So, our local authorities are willing to help, keeping their anonymity, helping with economic assistance to alleviate their financial and social problems.

4- It is very important the information and education community members at all ages and levels for these problems
5- In epidemiology the infected person is isolated. Let be such a thing even for the cases identified so far, to isolate a particular community, to take all the necessary facilities and thus to avoid the spread to a large extent.
6- It is needed the collaboration of all instances, it would be the best to know the case in order to be recognize and supported by everyone.
7- In the actual law changes can take place through legislative decrees. The doctor and the teacher must be aware of their patients/children they work with, so in order to respect their anonymity, the doctor and the teacher, should underwrite that if they get known the case they should keep secret the information, otherwise they will be punished.

Tirana, 2011