

Russian Red Cross  
Irkutsk Regional Branch

CHILDISH FACE OF A NONCHILDISH DISEASE  
Informational manual for specialists at boarding schools and preschool  
educational institutions for children affected by the epidemic of HIV-  
Infection

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Authors:

A. I. Zagainova, Epidemiologist, "Care and Support to PLWHA" Program Coordinator in Irkutsk

E. K. Berezovskaya, Pediatrician, Irkutsk Regional AIDS Centre

Advisors:

M. V. Akulova, Epidemiologist. Chair of Irkutsk Regional Branch of the Russian Red Cross

N. V. Ivanova, Epidemiologist, Irkutsk Regional AIDS Centre

E. S. Galenetskaya, Counselor, Mother and Child Health Protection Department, Head Department of Health Care of Irkutsk Region

L. E. Karkushko, Counselor, Preschool general and additional education Department, Head Department of general and professional education, Irkutsk Region

Reviewer:

I.V. Ivanov, MSPH, Director, Centre for Prevention of Youth Drug-dependency

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The given manual represents the information manual for the staff of preschool educational establishments - teachers, tutors, psychologists, medical nurses at kindergartens. In this manual modern representations are given about HIV-infection, described basic social and psychological problems of the families affected by HIV/AIDS epidemic. Special attention is given to questions of providing rights of HIV-positive children and the responsibility of the staff of children's establishments for observance of this rights/ Also a role of educational preschool establishments in preservation of quality of children's lives affected by epidemic of HIV-infection is described, as well as the concept of stigma and discrimination. This manual includes sections due to problems of HIV-positive women and children born to them, covered questions of prevention of social abandonment and lifestyle of abandoned children.

The edition is accessible to the broad audience of readers.

The foreword to the second edition.

One year passed after the publication of the first edition of this manual. During this period the number of children born to HIV-positive mothers increased and continues to grow. Unfortunately, the number of abandoned children touched by HIV epidemic also increases. These children become pupils at boarding school establishments (children's homes and orphanages). The staff at these establishments also experience need for the information on the problem of the HIV-infection as a whole, and on questions of the maintenance of children with the HIV-infection at children's establishments in particular.

With the help of this manual we broaden a target audience of readers by including staff of children's homes and orphanages.

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*There comes time when children, who were born to HIV-positive mothers, have reached the age of starting going to educational establishments. The number of such children in Russia steadily increases every year. At the same time research shows that establishments are not ready to work with children affected by epidemic of HIV-infection. The employees of preschool educational establishments experience a high degree of stigmatization in relation to such children and their families. Uncertainty and fear for the health and health of other children. They do not have enough knowledge on HIV-infection. In result teachers, tutors, psychologists and even medical workers at preschool establishments can involuntarily promote amplification of epidemic negative influences. For employees preschool educational establishments to become really effective link on mitigation of negative consequences of HIV-infection, today it is urgently required to increase their level of knowledge on a problem of HIV-infection. Also active involving of the staff at children's establishments in process of the organization of protection and support of children affected by epidemic.*

## INTRODUCTION

According to the Incorporated program of the United Nations AIDS Program (UNAIDS) today in the world there are over 40 million HIV-infected people. More than 3 million of them are children.

The epidemic of HIV did not skip our country. The epidemic of HIV in Russia started to be distributed from the mid 1980s when the first cases of disease appeared. A case of intrahospital infection of HIV in 1989 became widely known. More than 250 children in medical institutions in the south of Russia were infected. Since that time this unchildish disease has involved the most defenseless and vulnerable victims – children.

According to the official data as of beginning of 2007 in the Russian Federation there were over 350,000 HIV-positive people, more than 2000 were children. According to epidemiological calculations the real number of HIV-positive people some times exceeds these figures. The majority of those who were infected do not know about it. Experts consider that true scales of epidemic exceed the number of registered (that is confirmed by laboratory testing) cases of HIV infection 4-7 times.

In the nearest future the epidemic of HIV infection will have a serious impact on the economy of our country. The labour productivity will reduce because of loss of the most productive part of the population in the most able-bodied years of their life and also will increase the expenses burden for treatment and care for patients and orphans.

Till 2002 the basic mode of transmission of HIV-infection in Russia through injection. The epidemic basically affected injection drug users - youth at the age of 14 - 29 years old. During the past 2-3 years the number of new cases of HIV through sexual way has considerably increased. Today almost everywhere epidemic of HIV-infection has left the limits of so-called "groups of high risk" (injection drug users, men who have sex with men, and commercial sex workers). Now the epidemic affects absolutely all layers of society. Also educated and socially adapted (so-called "safe") groups of the population seriously suffer. There are those who bring the biggest contribution to economic and social development of the country. Today the most vulnerable groups of the population are women, youth and children.

According to experts (infectious disease specialists, pediatricians) in the nearest years the number of HIV-positive children will grow and also rate of death among them will grow. There is increase in the number of children who have HIV-infected parents and who may become orphans losing one or two parents. Many of these children probably will grow in conditions of an extreme poverty, social unfavorable and the isolation aggravated by a high degree of stigmatization which may be caused by disease of their parents.

Now in Russia the number of children who were born to HIV-infected mothers rather quickly grows. Part of these children will receive HIV-infection from mothers. But even those children who will have luck to avoid the diagnosis "HIV-infection" will experience all negative epidemic consequences.

*Human immunodeficiency virus (HIV) is a virus which penetrates into human body, gradually destroys immune system.*

## **Chapter 1**

### **HIV-infection: Up-to-date definition**

The immune system is responsible for protection of an organism from alien agents such as bacteria, fungi and viruses. This system plays a significant role in prevention of development of malignant tumor diseases.

The disease caused by a human immunodeficiency virus is called *HIV-infection*.

*AIDS - Acquired Immune Deficiency Syndrome*. This is a condition, which is typical, as a rule, for late stages of development of HIV-infection.

AIDS is manifested by a set of the certain diseases (infectious, oncologic) and the symptoms (signs) of developing owing to considerably weakened as a result of influence of HIV immune system. Among them there are such infections which never arise in the person with the intact immune system. These diseases are called opportunistic.

### **The modes of HIV transmission**

*AIDS - Acquired Immune Deficiency Syndrome. This is a condition, which is typical, as a rule, for late stages of development of HIV-infection.*

HIV is extremely unstable in an external environment. Outside of a human organism HIV quickly perishes from influence of high or low temperatures; any disinfectants in its usual concentration.

Human immunodeficiency virus (HIV) can be transferred from person to person only through the certain biological fluids of an organism (in other words, for infection of HIV there should be an exchange of biological liquids with high concentration of HIV between the sick and healthy person.

The risk of transmission of HIV depends on the quantity of viruses, which the biological fluid of the body contains and which the person is in contact with. The concentration of viruses is not the same for different periods of the infection development and different fluids of the body.

The biological fluids which contain the maximum concentration of virus (or concentration, which is enough for becoming HIV infected) are:

- Blood
- Sperm
- Vaginal secretion
- Breast milk

Biological fluids which contain very low concentration of the virus and so are not of any danger;

- Urine
- Tears
- Saliva
- Phlegm
- Sweat

In order to infect the person with HIV, the biological fluids containing HIV in maximal concentration, should directly get into blood or on a

mucous membrane. Virus introduction can occur through blood vessels (veins and another), anal orifice, rectum, vagina, penis (listed in reduction order in a degree of vulnerability). On the last place are cavity and the damaged skin: the risk of trans infection is very low, practically absent, because in cavity saliva renders an additional protection. The blood cannot absorb from the skin surface breaking free a wound from infectious and toxic agents.

**There are only three ways for HIV transmission:**

- Sexual mode of transmission

Today the sexual way of infection is rather urgent in transmission of HIV-infection and amounts practically 50% of new cases of HIV-infection.

Sexual mode of transmission takes place during any unprotected (without the use of condoms) sexual contact at any variations of sexual practices (anal, vaginal, oral).

- Parenteral mode of transmission “blood into blood”

This mode of HIV transmission takes place in case of using non sterile instruments or using the same needles and syringes, using injection liquids which contain blood of the infected person, transfusion of an infected donor blood and its components, etc.

At present the parenteral mode of transmission is spread among injection drug users (more than 90% of all cases of parenteral HIV-infections).

- From the infected mother to a child

This mode of HIV transmission takes place during pregnancy, delivery and breast feeding.

However, it is necessary to notice, that not all children who were born to HIV-infected mothers will be infected too. This mode of infection takes place only in 15-45% of cases if no special measures of prevention are taken. Using the full complex of preventive measures for pregnant HIV-infected women the risk of infection for future child could be reduced to two and less percent.

**HIV is not transmitted: through air, everyday contacts, fecal-oral (through food and water) and inoculable ways (through stings of insects)**

**HIV cannot be spread** through the following modes

- Kisses, embrace, sneezing, cough or conversation
- Hand shake, joint games, any kinds of activities including sport, co-education
- Nursing and caring for an infected person, including the child
- Household contacts, use of common household objects - utensils, towels, bed-clothes, a night pot, a toilet sink and so forth
- Sojourn in one room
- Using a bath, swimming-pool and so on
- Stings of insects or through animals

*The situations of possible transmission of HIV-infection from the infected child in everyday life practically do not exist. It proves to be true for more than 25 years of history of the epidemic.*

## Concepts of risky behavior, risk and vulnerability

At the present time, it is more correct to speak in connection to HIV infection not about “high risk groups” (high risk groups being defined as injecting drug users, commercial sex workers and men who have sex with men), but about high risk behavior (which can be practiced by any person without connection to any social and other group) and about vulnerability that most often lead to HIV infection.

Risk deals with conditions that lead to HIV infection. The definition of risk is universal: any person can be infected with HIV under certain circumstances when coming in contact with the virus. In principle the virus does not care to which social group a person belongs to or if the person’s behavior is considered socially acceptable.

Vulnerability is a relative notion which corresponds to the person’s capacity (physical, intellectual, social, cultural, economic, informational, educational, etc.) to respond to everyday risks in adequate way. Vulnerability depends on how well a person can control his life circumstances and can (or cannot) protect himself against HIV and its consequences. Low level of awareness of a problem, discrimination, hostile attitude of a community, lack of access to the information, medical, social, psychological assistance, poverty, lack of rights and other factors exert influence on a vulnerability level.

## Prevention of mother-to-child transmission of HIV

*Planning pregnancy assumes full medical examination of a married couple no less than 6 months before pregnancy, and qualitative carrying out of all complex of preventive actions can serve as a serious guarantee a birth of a healthy child.*

As it was said above, the risk of infection of fetus with HIV can be considerably lowered by carrying out certain preventive actions. The major preventive measures during pregnancy, delivery and feeding of the child are:

- Early registration of an HIV-positive pregnant woman at a women’s wellness center (it is desirable, not later than fourteenth week of pregnancy)
- Regular medical observation of a woman at a women’s wellness center and by a doctor at the AIDS Center or by an infectious disease doctor at any medical establishment of general profile.
- The social - psychological help to a woman. The help in overcoming of negative influences of stigmatization and discrimination
- Medical prevention with antiretroviral drugs (special medical products for treatment and prevention of HIV transfer) to HIV-positive woman during pregnancy, deliveries and also to a newborn child
- Modern and qualitative treatment at the pregnant woman of accompanying infections (especially sexually transmitted diseases, hepatitis and another)
- Correct and careful delivery, including routine cesarean section (in the absence of medical contra-indications)
- Change of feeding methods (if there is the opportunity, refuse

breast feeding)

- Change of a woman behavior to less risky (refusal of using drugs, smoking, unprotected sexual contacts during pregnancy, as it is possible, abstinence of sexual practice during the entire period of pregnancy)
- Psychological readiness of a woman to active collaboration with medical and social workers, orientation on her personal responsibility for a state of health of a future child

### **Prevention of HIV-infection among adults and teenagers**

Now the vaccine for HIV-infection still does not exist. However, thanks to intensive scientific researches the hope has appeared for development in the near future an effective vaccine against HIV. In perspective, the vaccination should become radical solution to a problem.

*HIV infection is typical "behavioral disease" of adults and teenagers. Taking into account the ways of transmission and of HIV-infection among the certain age groups of the population we could say that it is certainly "adult" disease, but not a childish one.*

But today, when all over the world annually millions of people are infected with HIV the only effective preventive means based on accurate information is *the change of each person's behavior towards less risky*. In Russia the same as all over the world, up to 90 % of all cases of HIV-infection happen only in following two situations:

- *Injection use of drugs through common needles, syringes or solutions of drugs*
- *Sexual contacts without use of a condom*

The model of behavior of an adult person or a teenager, his adequate choice (whether to use drugs or not, whether to use only sterile tools or not, whether to practice safe sex or not, whether to use a condom or not and so on) and defines a degree of his protection against HIV. Therefore the risk of infection of HIV among adults and teenagers can be considerably reduced if the following rules of behavior are followed:

- Not to use injection drugs
- Always use only for single use sterile tools (for injections, piercing, tattoo, etc.)
- To the extent possible to prevent situations when there is need for blood transfusion (for example, to avoid traumas of situations dangerous by way of occurrence, on a regular basis to be surveyed at the doctor for duly detection of diseases and purposeful assignment of therapeutic treatment, instead of surgical treatments, etc.)
- To receive services (medical, manicure, etc.) only at licensed establishments which guarantee qualitative instrument cleansing
- To refuse multiple and sexual promiscuity
- To refuse sexual conversation with people who practice risky behavior (e.g., drug users, commercial sex workers, etc.)
- To observe faithfulness to a sexual partner
- Always practice only protected sex (with use of a condom). In this case the condom should be considered as necessary and habitual means of hygiene of sexual relations

*Only observance of all rules of the behavior, responsible attitude to the health and to the life can considerably lower the risk of HIV infection and control dissemination of HIV epidemic.*

*Universal prevention measures*



*should be undertaken in contact with biological liquids of any child or any adult in spite of whether HIV-status is known or not.*

### **Emergency cases**

In the case of any "emergencies" (i.e. contact with biological fluid, for example at first-aid to the child if he is injured, has some traumas, nose bleedings, etc.) there are certain universal recommendations in process of preventive measures transfusion of HIV, hepatitis and other infectious diseases

### **Contamination with a biological fluid (first of all blood) of a skin surface:**

- Carefully to lavage with soap the contaminated area twice with flowing water. Also it is possible (but it is not necessary!) to clean this area with 3 % solution of chloramine or 70 % solution of ethyl alcohol

Injury of cutaneous covering:

- To squeeze a little blood from the wound
- To lavage the wound with running water with soap or with addition of manganese solution (0,05% solution of potassium permanganate - a solution of manganese is pale pink)
- To clean wound edges (70% solution of ethyl alcohol, solution of brilliant (ethyl) green or 5 % solution of iodine)
- To put on a plaster or a bandage. If a biological fluid (especially blood) got on conjunctiva:
- It is necessary to irrigate eyes with pure water (or with addition of 1% of a boric acid solution). You can drop the eyes (but it is not necessary!) with 10 % solution of sulfaaside sodium (albucid)

### **If a biological fluid (blood!) got on nose and mouth membrane (happens seldom):**

- It is necessary to drop the nose with 1% of protargol solution, carefully to rinse a mouth, if it is possible with the use of 0,05 % solution of pale pink color) potassium permanganate

If there was damage of mucous covering or skin surface by the sharp object which have traces of another person's blood on its surface (for example a puncture of a skin with another's needle), it is necessary also to receive a doctor's consultation at the AIDS Center and at local medical establishment to solve all question on medical prevention of HIV.

The contaminated linen (underwear or bedclothes), clothes, nappies, etc. with traces of blood or other biological fluids of the child should be soaked in a washing solution with addition of chloramide or other disinfectant in usual concentration; carefully to wash, dry up and iron. If it is necessary to keep the contaminated linen, it should be put in a plastic bag and tied up.

All manipulations - providing first-aid, change of linen, etc. is necessary to carry out in rubber gloves. After taking off gloves, always wash your hands with soap.

These requirements concern not only preventive measures of HIV-infection, but they are directed on prevention of occurrence of any

infectious diseases in children's group.

### **Indications for use of medical gloves**

Medical and pedagogical personnel should put on medical gloves in the following cases:

- Cleansing of damaged skin of a child
- Cleansing of mucous membranes of a child (cleansing of cavity, eyes, intimate washing)
- Sampling of blood and other biological fluids for study
- Carrying out medical manipulations at which the contact with blood is possible, mucous membranes secrets (injections, enema, stomach washing)

*Communication (if certainly it has no intimate character and does not assume joint use of injection drugs) with HIV-positive person, especially with a child is absolutely safely and does not demands any special protection measures.*

If the person who looks after an HIV-positive child has wounds on hands, they need to be plastered with waterproof adhesive plaster or to put on rubber gloves.

Medical gloves reduce the risk of development of infectious complications in child (if the gloves are sterile) and reduce risk of infection of HIV at the contact with blood and other biological fluids of an HIV-positive person.

### **Anti-epidemic regime at children's establishments collectives where there are HIV infected children.**

To prevent the infection of the personnel and also in case of joint stay of HIV infected and not infected children it is necessary to follow the order of Ministry of Public Health of USSR dated August 12, 1989 № 408 "About measures on reduction rate of incidents of viral hepatitis in the country"

Medical rooms at children's establishments should be provided with single-use instruments. In case of its absence – for multiple use tools are treated according to the order of Ministry of Public Health of USSR № 408. Carrying out disinfectant measures follows by Methodological instructions "Means and methods of disinfection and sterilization" expounded in the order of Ministry of Public Health of USSR from № 408.

### **Stages of development and manifestation of HIV**

*HIV infection is referred to so-called "slow diseases" is characterized by long-term flow, progressing lowering of immunity which can lead to development of AIDS and in result to death.*

HIV affects immune system of a person, first of all the blood cells - so-called CD4-lymphocytes which are responsible for organization of immune reaction of a body in general. If the person has caught a virus (became HIV-infected) does not mean, that AIDS at once will develop. Some years after infection with HIV (7-12 years and more) the person cannot feel presence of illness, feel like quite healthy, conduct a former active lifestyle, be quite capable. It is so-called asymptomatic period of HIV-infection. Modern methods of treatment can considerably increase the term of asymptomatic movement of HIV infection.

*The course of HIV-infection is*

However, it is a mistake to think that at this time in a body of an infected person nothing is happening. At first the body in reply to HIV introduction starts to develop virus-neutralizing antibodies which

*differs with big variety. Duration of the certain stages at different people is various too. Duration and character of development of disease depends on specific features of an organism. The style of life, mode of rest and work (loading, activity), the temper of nutrition and etc.*

*Right after getting infected during some time neither laboratory nor clinically it is possible to determine diagnosis "HIV-infection". However, it is necessary to remember that the person can be a source of infection from the moment of infection even sometimes without any slight idea about the danger.*

suppress freely circulating in blood viruses, but do not work on viruses taking place in cells. Step-by-step protective facilities of immune system work out and develop the condition which is called Acquired Immune Deficiency Syndrome (AIDS). There is an accumulation of free viruses in the blood, expressed amount reduction of immune blood cells – CD4 lymphocytes. Due to immunity decrease and as result an HIV-infected person faces various diseases which are called secondary - infections (including opportunistic), tumours, affection of various organs and systems which become cause of death.

The description of stages HIV which adhere in Russia is developed by academician V.V. Pokrovskiy. Dynamics development of illness includes five stages: stage of incubation or the "window period", stage of primary manifestations, subclinical (latent) stage, stage of secondary manifestations and a terminal stage.

The period which begins from the moment of penetration of a virus in the organism and lasting on the average from 1,5 to 6 months, name 1 stage - *a stage of incubation* or «*the window period*».

With infection of HIV the majority subjectively do not feel any painful tenses. Antibodies to HIV also appear not at once, but only after some time after an infection. Laboratory confirmations of the diagnosis "HIV-infection" becomes authentic only after certain time – at minimum from 3 weeks to 3-6 months (sometimes this period stretches up to 12 months and even more), which is necessary for the body immune system to develop antibodies to HIV («*the window period*»).

In most cases, in 3-6 months from the moment of infection begins II stage – *a primary stage*. This stage can be expressed differently. Can be found out antibodies without any symptoms of illness, but most frequently there is fever, eruption rash on skin, mucous membranes, and growth of lymph nodes. The symptoms of primary stage of HIV-infection are similar to the symptoms arising with many other infectious diseases. Frequently 1-2 symptoms take place simultaneously in different combinations. At this stage secondary diseases can appear, such as herpetic and yeast infections, etc. As a rule, they are expressed poorly, proceed quickly and treatable. Duration of primary stage can differ from several weeks to several months. In general duration of II stage takes about a one year.

In most cases, the primary stage transfers into III stage - *subclinical*. Sometimes it is called hidden, because frequently a unique symptom of illness at this stage is the growth of lymph nodes, thus they are painless and practically do not cause any unpleasant sensations or inconveniences. On this stage the speed of duplication of HIV is slowed down. It is connected to superfluous reproduction of protective cells. Duration of a subclinical stage is very variable and can be from 2-3 to 20 years, on the average it lasts for 6-7 years.

The IV stage is *a stage of secondary diseases*. Occurrence of some infectious and non-infectious diseases is typical for this stage. More often, it is various mucous and skin affections, inflammatory diseases of upper air ways, a gastrointestinal tract, malignant new growths and

some other.

The V stage - *terminal* - is characterized by generalization of secondary diseases which accept heavy and incurable forms.

### **Peculiarities of the course of HIV-infection in children**

*Adults who care about a child and his/her education, should closely and constantly observe development and state of health of a child in time to notice any deviations or alarming signs and immediately to address the doctor.*

The course of HIV-infection in children is more severe than in adults. Acquired Immune Deficiency Syndrome (AIDS) can develop faster and will come to the moment when the child will require specific antiviral therapy, special medical supervision, and special care.

The course of HIV-infection has a number of features. Children more often than adults have bacterial infections and respiratory infections develop faster. The most common clinical signs of HIV-infection are encephalopathy and retardation of development of psychomotor and physical rates. Frequently there is thrombocytopenia which is externally shown as hemorrhages on skin and mucous and can cause, in some cases, death.

The first signs of possible progressing of HIV-infection and deterioration of child's condition can be as backlog in psychological development, discrepancy of growth to age, infringement of an increase of weight, increase in the sizes of liver and a spleen, growth of sub maxillary and inguinal lymph nodes, frequently repeating of yeast or herpetic infections of a mouth cavity. Similar conditions demand immediate consultation of a doctor.

### **Physical development of children with HIV-infection**

Physical development is an important indicator allowing to estimate not only harmonious development, but also possible presence of HIV-infection, and degree of illness progressing.

Physical development - dynamic process of changes in a body, size, proportions, muscular force and serviceability. For an estimation of physical development the anthropometry is used - measurement weight-growth indices at particular moment of time. The control of physical development is carried out as a result of dynamic care.

If the child shows abnormal increase in weight or if there is no increase in weight (flat weight curve line), it indicates the malnutrition of a child or possible acute infections. It is necessary to carefully examine the child to identify diseases or problems and to treat them.

Loss of 5% of weight (a negative weight curve line) testifies about deterioration of condition of an HIV-infected child and possible necessity of special antiretroviral treatment.

### **Estimation of psychological development of HIV-infected children**

Infringements of psychological development and loss of acquired skills frequently are observed when HIV-infection progresses. As a rule, the result is HIV-encephalopathy (disease which develops in case of direct affect of brain tissues by HIV) when gradual loss of already acquired skills is observed.

The progressing encephalopathy includes, at least, one of the herein

*For an estimation of psychological development of children older than 3 years it is necessary to take into account their skills and conformity to the age. For diagnostics of HIV-encephalopathy the estimation of an emotional condition of a child, his propensity to knowledge and his memory has the great value.*

provided symptoms which are present within 2 months and more at absence of other diseases, except HIV-infection, explaining these symptoms:

- a) Infringement of attention or loss of skills or intellectual functions, which reveals at standard neurologic examination or with the help of neurophysiology tests.
- b) Infringement of brain growth or acquired microcephalia (the small sizes of a brain), reveals at change of shape of a brain, or atrophy of a brain. It can be revealed with computer or magnetic-resonant tomography.
- c) Acquired symmetric impellent frustration: the weakness of extremities, pathological reflexes, misbalanced and chaotic movements, etc.

In

HIV-infected children the infringement of psychological development can be connected with adverse current of pregnancy and deliveries, the use of alcohol, drugs. In this case the development will be behind of age norms, but will be forward whereas with HIV-encephalopathy (mental deficiency) the child regresses (loses skills).

Lesion of the central nervous system can also develop as a result of transmission of various infections - meningitis, encephalitis of various origin (viral, yeast, bacterial Bacterial, caused by cytomegaloviruses or viruses of a herpes, mushrooms of a sort кандиды or the elementary, is more often than others - a current - соплазмой). In this case occurrence of neurologic infringements will be precisely connected to a sharp heavy infectious disease of a child.

The estimation of psychological development of children of the first 3 years of life can be carried out under tables of development of motor and mental skills (see appendix 2).

At progressing of HIV-infection with affection of the central nervous system at the children can worsen the mood, lose the interest to surroundings, become apathetic, speak a little, cease to ask questions, badly remember the information (verses). Children of school age can lose abilities to learning.

### **Diagnostics of HIV-infection**

The diagnosis "Hiv-infection" can be exposed only on set of *the epidemiological data* (presence in human life the facts of risky behaviour and/or a situation of risk of HIV-infection), *the laboratory data* (the positive test for antibodies to HIV) and *the clinical data* (examination of a patient).

Now for laboratory diagnostics of HIV-infection uses various methods of detection of HIV. The most widespread, accessible and authentic method of laboratory diagnostics of HIV-infection is the standard method of detection of *antibodies to HIV* in blood analyses.

### **Interpretation results of laboratory diagnostics of HIV**

Results of researches on HIV are interpreted as positive, doubtful and negative.

*Negative* results of analyses when are not found the antibodies to none

*It is important to understand that with estimation of psychological development necessary to take into account the adequacy of education of a child and to be*

*convinced that backlog in development is not connected to pedagogical neglect, hospitalism, hearing or sight disorder.*

*The majority of children born to HIV-positive women will not be infected with HIV. However right after birth of the child by HIV-infected mother cannot be established whether he infected or not.*

*From the moment of birth till the moment of an establishment of the final diagnosis (i.e. till 18 months) the child who was born to an HIV-positive mother will have the diagnosis «Prenatal contact on HIV-infection».*

of the antigens (proteins) of HIV. In this case the conclusion of absence in the given blood sample of antibodies to HIV (but not about absence of the disease!). Taking into account « the period of a window» the negative result cannot be interpreted as absolute absence of HIV-infection.

*Doubtful* (uncertain) will be considered the results of research which cannot be interpreted authentically. The doubtful result of the analysis shows that laboratory survey is necessary to be repeated.

*Positive* results are considered to be those which authentically prove the presence of antibodies to HIV in blood. The positive test for HIV testifies that the person is infected with HIV. Such person is HIV-positive or HIV-infected.

### **Laboratory diagnostics of HIV-infection at children born to HIV-positive mothers**

All children born to HIV-positive mothers right after birth have positive result analyses of blood on antibodies to HIV, in blood of all children in has maternal antibodies which smaller then HIV virus and can penetrate through a placenta barrier. But antibodies cannot be the cause of HIV-infection.

Maternal antibodies are collapses during some time. If the child was not infected with HIV during pregnancy, delivery or as a result of breast feeding, then to 15-18 months the result of blood analyses on antibodies to HIV become negative.

Nevertheless If the transmission of HIV from infected mother to her newborn child took place, in 15-18 months the results of analyses on HIV antibodies will stay positive. It means that at the child develops his own antibodies on preens in blood human immunodeficiency virus (HIV).

Also there are methods of earlier laboratory definition of DNA and RNA of HIV in blood which allow authentically establish the diagnosis "HIV-infection" at the majority of infected newborns to age of 1 month and practically at all infected children to age of 6 months. But the final laboratory diagnosis of HIV-infection can be established in the age of 15-18 months only after carrying out of standard laboratory researches on antibodies to HIV, other laboratory researches and survey of the doctor.

In 18 months after the laboratory researches and survey of the doctor, defines the HIV-status of a child: positive (the child is infected with HIV) or negative (the child is healthy concerning the HIV-infection). All children who was born to HIV-infected mothers should be on dispensary supervision till the age of 18 months. After this term on the basis of survey data and results of laboratory researches the commission makes decision to shrink the HIV-negative child off the dispensary register on HIV. In this case from medical documents of HIV-negative children any mention of HIV-infection should be removed. It makes to protect the child and his parents from displays of stigma and discrimination from community, first of all, medical and pedagogical workers.

## Chapter 2

*Antiretroviral treatment cannot cure completely, but can considerably lower frequency of co-infections and opportunistic diseases in HIV-infected people, allows prolonging work capacity of people living with HIV. Treatment has made the prevention of mother-to-child transmission possible.*

**Treatment of HIV-infection** Unfortunately, today there are no ways of treatment of HIV-infection which would lead to full removal of virus from an infected organism.

Modern drugs for treatment of HIV-infection (so-called antiretroviral drugs) are aimed at delaying development of the disease, at interfering with duplication of the virus in the body.

Adherence to taking the necessary medications and healthy life style, can considerably prolong the life of a person with HIV-infection and to keep his quality of life for a long time.

The significant value for process of prolongation and maintenance of quality of life of HIV-positive people (especially children) has *healthy style of life*: healthy diet, adjusted physical exercise and good rest; for adults: saying no to drugs, alcohol, smoking; psychological comfort and appropriate care. Regular medical supervision and examination will help to prevent or timely to find signs of co-infections. All these moments also can be promoting an increase of efficiency of medical treatment of HIV-infection.

The main principles of therapy for a person with HIV-infection:

- Timely beginning of antiretroviral therapy and prevention development of co-infections
- Timely treatment of secondary diseases. Early diagnostics is necessary for that reason
- Necessity of creation of protective psychological regime
- Dispensary observance of HIV-positive people (first of all, it concerns children since disease can progress faster and proceed in a more severe form. Therefore it is necessary to notice as soon as possible first signs of trouble and to appoint treatment in time).

### Antiretroviral treatment

Now there are four classes of antiretroviral drugs, which are used for treatment of HIV-infection. Effectiveness of antiretroviral drugs is based on blocking special substances - enzymes which the virus uses during the duplication.

Simultaneous appointment of 3-4 antiretroviral drugs to the maximum extent suppresses ability of HIV to duplication and refers to «*highly active antiretroviral therapy*». The treatment with one or two antiretroviral drugs is prescribed if for any reason it is possible to carry out more intensive treatment, and it is prescribed for pregnant women to prevent transmission of HIV to a newborn.

Unfortunately, all antiretroviral drugs have disadvantages. They:

- Cause unpleasant, occasionally heavy, side effects
- Require constant (*lifelong*) taking medicine (except cases taking medicine for preventive maintenance of transmission of HIV to a newborn)
- Demand *very accurate adherence to taking them* (otherwise resistance develops - immunity of HIV to medicine)
- Can cause fast accustoming of virus thus ceasing the

*For prevention of mother-to-child transmission of HIV and for treatment of HIV-infection antiretroviral drugs for pregnant women and children are provided free by establishments of Healthcare (in women-children's wellness clinics, maternity hospitals, local AIDS Centers, etc.)*

usefulness

- The majority of drugs are expensive and inaccessible

Indicators for assignment of antiviral therapy the scheme are defined by treated physician according to a clinical stage of disease and results of laboratory testing.

**The conditions for maintenance of efficiency of antiretroviral treatment:**

1. *Duly assignment of antiretroviral drugs* (it is necessary for the child to be under constant supervision of doctors)
2. *The prescription of the optimal scheme of treatment* (according to combination and doze of medicines)
3. *Careful observance of the scheme* (psychological and practical training of people who take care of children - parents, trustees, medical staff, teachers, etc. - on issues of accurate and close adherence to treatment, including time, doze and connection with meals)
4. *Doctor's examination and laboratory testing before the beginning of treatment* (defining indications and contra-indications to medicine assignment)
5. *Regular supervision of a child* taking antiviral drugs (supervision is carried out by the peditrician to evaluate efficiency of treatment)

Continuous duplication of HIV is connected to high frequency of formation of different strains of a virus, and if the antiretroviral therapy is not effective enough, then the process of forming resistance progresses.

The most significant in practical value factor leading to reduction of therapy efficiency is *not following the prescribed regimen* (the child should regularly take not less than 95 % of the prescribed doze of a medicine; besides time, it is necessary to follow specific recommendations on taking medicine).

Taking into account the importance of adherence to treatment, before the beginning of treatment it is necessary to provide counseling to people who look after children with HIV.

It is necessary to pay attention to:

- Peculiarities of storage and dosage of medicines
- Careful observance of time for taking drugs
- Necessity to take drugs during meals
- The combination with other medical drugs and some products

These questions should be adjusted during the treatment process as well.

**"Non-traditional" therapy**

So-called «non-traditional treatment» (massage, acupuncture, homeopathy, bionics, etc.) the same as the traditional medicine,

*Antiviral therapy is difficult complex treatment which is appointed for all life. Than more effective scheme of treatment is appointed, than punctually recommendations on taking drugs, than higher the level preparation of the personnel of children's establishments and parents on observance of mode treatment, then the child have more chances that he will live a long and happy life.*



cannot cure the HIV-infection, but can strengthen and, in the certain degree, to improve an organism of HIV-positive people, slowing down the development of disease and facilitating some painful conditions connected with HIV-infection.

*However it is necessary to remember, that non-traditional treatment cannot replace the antiretroviral therapy!*

### **Adherence to antiretroviral treatment**

*The adherence understands as realized and diligent participation of the patient in mutuality to himself. If it is a child then «realized and diligent » to carry out doctor's instructions should adults who take care of the child.*

Adherence means more than just «observance of instructions»; it means understanding by an adult the meaning of actions, sincere desire to care for a child and to cooperate with medical workers. To suppress duplication of a virus and to avoid resistance to drugs variety it is necessary to observe the scheme which means accurate observance of time, doze and diet (some drugs are taken only on an empty stomach, others together with food, etc.). If patients miss dozes or irregularly take drugs the virus can develop the resistance and medications will turn ineffective. In other words, to miss the time and doze of medications for an HIV-positive person is worse than not to get treated at all.

*For the patients who take antiretroviral drugs the key to success treatment is adherence to therapy.*

It is most difficult to achieve adherence in children and in people who take care of children. Commitment is required of adults, and participation within powers of a child. The degree of participation of a child in rendering assistance depends on his age and his mutual relations with adults. Pediatric medical forms do not always suit for babies and senior children. Many drugs have unpleasant taste; frequently it is difficult for children to swallow tablets. Giving the child medicine adults should measure exact volumes of liquid medications, to make small tablets, to open capsules, to dissolve drugs in water. With more than one person caring for a child, additional difficulties appear, both with treatment and with formation and maintaining adherence, and also with keeping secret about HIV-status of a child.

Help for HIV-positive children, especially children who live at boarding schools, means to pay attention to problems of adherence of the staff and special skills on strengthening of this adherence.

*It is really difficult to treat HIV-positive children really, but antiviral therapy really rescues children's lives and for the sake it is necessary to overcome barriers and obstacles.*

The central component of any pediatric help is cooperation between doctors, who take care of a child or a group of children. Such cooperation becomes especially important for children with HIV-infection. Without it antiretroviral therapy for children is doomed for failure. The doctor cannot simply write out a prescription and tell a child to take this drug, suppose, two times a day. One more key figure is necessary for successful treatment - the informed, disciplined and responsible adult person, who takes care of a child directly. The best way is when all people who look after the child are trained on rules and skills of antiviral therapy and precisely know the answers to the following questions:

### **What medicines will be given to a child?**

It is absolutely essential for people who take care of children is to know chemical or international names of medicines. However they

should learn to distinguish the drugs and to know how to keep, dose and take each of them. This issue is not easily solved, especially with pediatric forms of medications: in particular, all antiretroviral drugs which are produced as syrup have the same color. Therefore it is important to think over the system of marks (multi-colored labels, precise inscriptions). The medical worker at a children's establishment could provide valuable help to nurses.

### **When will the medicines be given to a child?**

*The miss of taking medicine or not on strictly established time it is intolerable and criminally in relation to a child!*

It is necessary to learn from a medical worker about a mode of taking drugs in connection with taking food: some antiretroviral drugs should be taken on an empty stomach, whereas others - with food.

It is useful for the people who take care of the children think over using timers, alarm clocks, mobile phones, etc.

The adults who are responsible for children's health should know precisely, in what time the medicine should be given!

### **How will the medicines be given to a child?**

*In Appendix 1 you will find practical instructions on maintaining adherence to antiviral therapy in children.*

Forming adherence to antiretroviral therapy in children can be difficult. Therefore the issue of antiretroviral therapy in children deserves the most detailed discussion and training of practical skills among the staff at children's establishments. The people who take care for children should know:

- How to measure the necessary doses
- Whether it is necessary to make small tablets or simply to divide them into parts
- How to measure liquid medicines - with measuring glass or syringe
- How to give the child medicine separately or together with food
- Whether it is necessary to hide somehow the bitter taste of this drug and how to do it
- Whether it is possible to take all medicines simultaneously
- What to do if the child has spat out a medicine or he suffers from vomiting
- How to teach a child to swallow a medicine correctly
- How to carry out «the first test» of taking medications to find out how the child reacts on medications
- How to develop and use system of encouragement of the child for being obedient taking medicines
- What to do if the next taking of medicines has been missed for any reason

The staff at children's establishments can make the process of taking medications easier, if they use written instructions, visual aids, video films and all appliances, for example, containers for pills, first-aid planners-organizers, measuring glass and syringes with marks, etc. Medical workers at children's establishments should conduct practical

classes to train the personnel who take care of children and who are presumably involved in the process of setting up and organizing the course of antiretroviral treatment for children.

*The goal of dispensary supervision over HIV-positive people is to provide them with timely medical help (early diagnostics, preventive maintenance and treatment of co-infections) and psychological support.*

### **Dispensary supervision**

It is recommended to HIV-positive people to be on dispensary supervision, i.e. to go through medical examination during certain periods of time.

Examination of people living with HIV-infection within the framework of supervision should be carried out upon their voluntary and informed consent and examination of children - with the agreement of parents or their legal representatives. Terms, plan and volume of examination will be defined by the physician depending on the stage of HIV-infection.

### **Creation of protective psychological regime for HIV-positive people**

Confirmation of the diagnosis causes in an HIV-positive person and his/her relatives heavy emotional reactions. At the same time in public consciousness there is prejudice towards HIV-infected people.

Infection of HIV entails serious consequences of emotional and social character that leads to deterioration of physical health. From the moment of suspicion about being infected with HIV-infection the person is exposed to constant psychogenic stress that dictates necessity of acceptance of measures for mitigation of medical and social consequences of such stress.

## **Chapter 3**

### **Social and psychological problems in families affected by HIV-infection**

*The child born to an HIV-infected mother always lives in conditions of social and psychological stress his parents and relatives experience in connection to HIV-infection.*

### **Problems of HIV-positive people during certain periods of the development of the disease**

Life with HIV brings serious trials, as the first day of detecting the diagnosis is followed-up by acute experiences. Certainly, due to their age, children cannot always understand the reasons for the "special" attitude, but they always *feel* this special attitude and react to it.

There are crisis situations which are common for any person living with HIV: an adult or a child. All these situations are connected with emotional losses, deep negative experiences. As a rule, it is impossible to overcome these situations, and people living with HIV, as well as members of their families need professional help of psychologists, social workers, teachers, and doctors.

Many years of studying peculiarities of social - psychological adaptation of people living with HIV at various stages of their life have shown the presence of correlation between the course of infection and how people adapt to new conditions. These supervisions led to defining *three main periods* in life of people living with HIV and members of their families when they are especially

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psychologically vulnerable and require support.

**The first period: statement of HIV-positive status in an adult or a child**

The diagnosis "HIV-infection" is a heavy stressful factor both for an HIV-infected person and for members of his/her family. The announcement of the diagnosis to the pregnant woman or the diagnosis of the child to his parents or trustees leads to a mental trauma. But the state of health of an HIV-infected person can be quite satisfactory. During this period on the foreground emotional experiences come, which can lead to increase of risk of development of various forms of suicide behavior in adults, to increase risk of abandoning a child or risk of his artificial isolation.

An HIV-infected mother can experience different negative feelings, for example:

- Anxiety (about possible infringement of confidentiality, impossibility to change something, etc.)
- Fear (about possible infection with HIV of relatives or threat of premature death of herself or the child, etc.)
- Concerns (about availability of treatment or an opportunity to save one's social status, etc.)
- Feeling of loss (plans for the future, position in a society and in family, financial stability, physical attractiveness, health, independence, etc.)
- Grief (about the expected or accomplished losses)
- Feeling of fault (in relation to people who she could infect, especially in relation to own child or people whose life "was broken" because of the infection)
- Remorse (because of one's own behavior which resulted in infection)
- Aggression (in relation to a specific person - to a suspected source of infection, or to a society in general)

**The second period: occurrence of clinical signs of the disease**

Natural course of HIV-infection implies that sooner or later the stage of progressing of the disease begins. During this period psychological vulnerability of HIV-positive people and members of their families raises again. For the first time the HIV-positive person and members of his family start «to feel presence of the virus».

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Serious painful symptoms, necessity of hospitalization become a hard trial. Many are afraid that henceforth their life will be connected only with constant pain, medicines and hospital. The fact of staying on treatment at an infectious disease hospital or a hospital of the AIDS Center can reveal the HIV-status for immediate and familiar people, not allowing to keep the diagnosis in secret.

Mother's or her child's state of health often requiring long stay at medical establishments frequently forces her to give up work or to stop studying. During this period psychological crisis aggravates due to a number of social problems: fall of career, occurrence of real material and financial difficulties, change of social roles in family (for example, senior parents are obliged to look after their adult children or juvenile children should carry out duties of adults), etc.

The necessity to start regular treatments with antiretroviral drugs can oppressively impact an HIV-positive person and members of his family. Many are frightened with complexity of taking medicines, side effects from taking antiretroviral drugs.

Severe illness or death of a dear person, child having the HIV-positive status, can cause intense psychological shock. Thoughts about possible approximation of own death or death of a child sometimes lead to serious aggravation of emotional crisis.

### **The third period: the terminal stage of HIV-infection**

During this period severe irreversible diseases develop.

The experience of working with people in terminal stages of the disease shows that despite the infringement of memory, delay of rate of current of mental processes, decrease of volume of aural-acoustic perception, weakness of judgments and conclusions, difficulties at setting of cause and effect relationships, third of patients with the HIV-infection keep painful experiences concerning fast death and requires psychological and social support.

Children of certain age also can be aware and understand their life situation and be frightened of death.

Relatives and family members of an HIV-positive person also need support and help.

### **Family and social problems of HIV-positive people:**

One of the most serious crisis situations is the problem of "disclosing" of HIV-status before relatives and close people. An HIV-positive person's the relations with friends and colleagues can become worse because of fear of disclosing of HIV-status and the status of the child, "anticipation" (as a rule, exaggerated) of forthcoming rejection, refusal in support, etc.

"Concealment" by one of spouses of the HIV-status brings in family relations a shade of understatement, tension, suspiciousness. Finally, «belated exposure of secret» even more worsens the conflict. All this is very well felt the children who become involuntary victims of the situation.

In the families affected by HIV, it frequently happens that

*Not always the family can independently cope with arising problems, especially when an HIV-infected adult member of family loses working capacity and opportunity to support family financially. In that case the help of social protection authorities and support of the nongovernmental organizations can be needed.*

matrimonial relations become complicated; there is also atmosphere of mutual mistrust, conflicts, threat, and in some cases, decomposition of family. Frequent are the situations when the closest people (parents or the spouse) cannot "accept" the diagnosis of an HIV-positive woman and her child, refusing help and support.

Frequently the family, because of illness of HIV-infection in one or several its adult members, loses the social status and material welfare. Care for child's health can require from mother and the rest of the family additional efforts, both physical and emotional, and sometimes financial especially in cases when HIV-infection is identified in a child and condition of his health worsens.

The feeling of loneliness of HIV-positive people is quite often aggravated with self-isolation when the presence of close person and an opportunity to talk to someone about the fears and doubts is especially necessary for them. Sometimes HIV-infected parents are so afraid of "exposure" of the diagnosis of the child and negative attitude of surrounding people that prefer "to isolate" themselves and the child as much as possible having reduced his communication both with peers, specialists, and the whole world. It cannot but negatively influence child's development and his health condition. Besides the negative effect on child's condition and development can be caused by impossibility for an HIV-positive mother to provide wholesome care for her child.

Today also there can be serious problems with registering a child affected by the epidemic of HIV at children's educational establishments.

Impossibility to register a child at a kindergarten, in some cases difficulties arising with employment of mother and as a consequence - deterioration of financial situation of family, fear for physical and mental health of a child, dissatisfaction with quality of care of a child and the attitude at children's educational establishments - all this forms specific complex of social - psychological problems of families affected by the epidemic of HIV-infection.

### **Children affected by the epidemic of HIV-infection.**

The term «children affected by the epidemic of HIV-infection» means not only those children, who are personally HIV-infected (any mode - from infected mother, parenteral or sexual). The children who have the close HIV-infected relatives and live together also apply to this category. The special place among these children is taken by children who were born to HIV positive mothers.

Irrespective of whether the child or his relatives infected with HIV, public out casting and stigmatization (including from medical workers, teachers, neighbors, colleagues of parents, peers, etc.) pursue all children affected by epidemic of HIV-infection, creating number of social - psychological and pedagogical problems, which can harm health and development of children.

### **The announcement to the child about his disease or disease of his**

## **relatives**

*There are common rules of communication with a child on difficult topics. It is necessary not to forget that each child is an individual and it is necessary for the teacher in cooperation with parents to develop individual strategy suitable for a particular child. It is necessary to talk with children of different age separately: children are at different stages of development, they need different volume of information, they have a different lexicon and they are interested in different questions.*

As the child grows up, sooner or later there will be a problem when and how to inform the child about his diagnosis or about the diagnosis of his mother or a member of his family. No matter how it is difficult to discuss the issue of HIV/AIDS with the child, it is necessary to do it. Probably in this case parents and teachers will need the help of the psychologist.

The majority of children at elementary school and even children of "kindergarten" age already heard about this problem. Though children learn about AIDS existence rather early, their perceptions are far from the reality and more similar to horror films. Before starting conversation with the child about HIV-infection it is necessary for each adult to receive accurate information about the disease. Probably, there will be a necessity before conversation with the child to receive consultation from the expert (the doctor at the AIDS Center, psychologist, and teacher) or from parents who have the same problem, which they successfully cope with.

Conversation about HIV-infection should become basis for conversation about safe behavior of the child with the purpose to protect oneself and others.

It is always uneasy to speak on similar topics with the child. However the child doesn't live in a vacuum. When he watches TV, looks through magazines, communicates with other children he receives various, frequently incorrect, information. If not, to start to discuss with the child difficult questions as soon as possible, another person, probably, not competent person will undertake this task. Unfortunately, many parents and teachers not only refuse children in reliable information, but also deprive themselves of an opportunity to make this information corresponding to those moral and ethical principles which they would like to impart on children.

A child may come up with a question to the educator or parents only in the case when he feels he can do it. It is necessary to create an atmosphere of openness and trust in which a child can ask any question on any subject not being afraid of consequences. It is necessary to support, to understand and encourage children to ask questions. It is necessary to provide children with the information which is exact and suitable for their age.

## **Chapter 4.**

### **Children born to HIV-positive mothers**

#### **Socio-psychological problems of pregnant HIV-positive mothers**

The problems of children root into the problems of their HIV-positive mothers.

An HIV-positive pregnant woman is under great stress, because a pregnancy itself is a strong stressful fact, and a pregnancy with HIV is evaluated by psychologists as catastrophic level of stress.

The high level of stigmatization and discrimination against all the HIV-infected people, especially against pregnant women, provokes the situation when many HIV-infected women prefer to «disappear» from field of view of the doctors till delivery. And it compromises the health of the baby.

Concerns about her own health and the health of her child, disapproval and censure of the immediate relatives, negative attitude of the doctors, and lack of knowledge about HIV-infections – all these factors can provoke the woman to abandon the child after delivery.

The majority of the children born to HIV-positive mothers do not differ from the other children in physical and mental development.

Such difficult situation engenders a whole number of medical, social and psychological problems, which immediately can affect child health level and its future at all. Problems described significantly worsen physical and psychological health of the woman, increase the risk of HIV transmission, lead to break of family relationships, and provoke abandonment of the child.

An HIV-positive pregnant woman has to meet a lot of challenges. At that time, when woman needs help and support of nearest and dearest people, she has to solve the problem – whether to tell them about her «terrible» diagnosis or not. She fears the negative reaction of her relatives, friends. Sometimes the negative reaction of her husband or relatives makes the woman terminate pregnancy or make a decision about abandonment of her baby.

Despite the fact that a woman always has the right of alternative choice – to terminate pregnancy or not, the necessity to make a decision is very hard and important step for an HIV-positive pregnant woman, especially under general censure and psychological pressure.

An HIV-positive pregnant woman can feel fear for her future, also she can have the lack of self-confidence, especially if she is very young, without financial benefit and education; if she has not so many friends and relatives who can help her and support in difficult times, or if the woman did not have any sources of financial and social support.

The necessity for taking antiretroviral medicine for prophylaxis of HIV transmission to the fetus can lead to side effects or just become for pregnant woman «very unpleasant and hard» process, which in turn can put obstacles in the way of formation positive relation to her expected child and maternity in general.

### **Children born to HIV-positive mothers**

At the end of 2006 in Russia there were 35,000 children born to HIV-positive mothers. According to specialists in medical sphere in a few nearest years the number of children with perinatal (antenatal) HIV-transmission most probably will increase annually. The factors that influence the development of this process are the following:

- Continuing growth of the number of HIV-infected women, the majority of them are at childbearing age
- Probable increase of birth rate among HIV-positive women.

Children born to HIV-positive mothers very often have impairment of innate immunity in connection with the fact, that their mothers are HIV-positive. All the children born to HIV-positive mothers are more vulnerable to different infections and more frequently suffer from severe forms of infectious diseases (including infantile infections). The impairment of innate immunity is the reason of high index of mortality among this group of children.

And although these children in connection with innate immunity are often born with weight deficit and broken health, good care for them can quickly fix up all the indexes of physical and mental development. Of course, the situation can be different. For example if the mother is narcotic/alcohol addict and keeps asocial way of life. In this case the birth of a healthy child is rather doubtful. And first of all it will be



connected with psychostimulant use by the mother before, during and after the child birth. As a rule, such children have physical and mental retardation.

### **Prophylactic medical examination of the children born to HIV-positive mothers**

The child born to HIV-positive mother should be under careful medical check-up from the very delivery to have good health and development.

Many researchers show, that correct care for an infant born to an HIV-positive mother, qualitative medical supervision, access to necessary medicines, care and love, family support of nearest people and people around can help the child to have complete physical and mental development and significantly improve quality of child's life. During regular medical check-up the following activities should be conducted:

- Counseling for a mother about infant feeding, caring for a child
- regular medical check-up by pediatrician and infection disease doctor at the AIDS-Center
- timely prescription of antiviral therapy
- social and psychological support for an HIV-positive mother and her child

Ambulatory care, emergency care and consultations for the children born to HIV-positive mothers should be provided by the local children's polyclinic without any restriction.

Prophylactic medical examination of children born to HIV-positive mothers should be taken by the specialists from the AIDS-Centers jointly with a pediatrician from the local clinic.

The children born to HIV-positive mothers and left without parental care should be sent to the medical establishments (orphanage) *on the general basis*.

Prophylactic medical examination of children with HIV is carried out by a pediatrician from the AIDS-Center. Medical examinations, outpatient care and emergency should be also in home-based setting, the special medical care – in profile medical establishments *on the general basis*.

### **The maintenance of physical and mental health of children born to HIV-positive mothers**

The children born to HIV-positive mothers always need systematic medical supervision, sensitive and loving care, qualitative nursing, valuable and rational feeding in compliance with the age, timely detection and treatment of diseases and painful symptoms, which are connected with immunodeficiency to maintain good physical condition.

Special emphasis for adequate mental development of the child is constant communication, games and developmental pastime holding. Just this lack of communication is the main reason of substantial developmental physical and mental retardation of «abandoned» HIV-positive children born in our country (in Irkutsk, in particular). In most cases these phenomena were not innate, developmental retardation was the result of artificial isolation of the children, who

had to live in inpatient care establishments for their first 2-3 years of life. And this very fact led to socio-pedagogic neglect and health conditions, which often were nonreversible.

The isolation of the children born to HIV-positive mothers was not connected with the inflectional danger from these children during the care or communication with them. It was connected to unavailability of the state structures and establishments to solve the problems of HIV-infection, and also scarce information awareness about HIV of medical community and the society in general.

## **Chapter 5.**

### **Maintenance and care for an HIV-infected child at children's educational institutions. The role of children's educational establishments in maintenance of life quality of children with HIV**

#### **Arrangement of the children with HIV-infection at children's educational establishments.**

The legislation of the Russian Federation prohibits the denial to accept the child at children's establishments because of HIV-infection.

Nowadays there can be serious problems with arrangement of the children with HIV infections at children's educational establishments because of refusal (often groundless and illegal) by the authorities.

All the children born to HIV-positive mothers, independently of presence or absence of HIV-infection, should be accepted at children's institutions *on the general basis*. To register a child at a children's educational establishment (e.g. kindergarten) parents or legal representatives (guardian) should:

- apply to the Department of Education with these documents:
  1. Passport of one of the parents
  2. Birth certificate of the child
  3. Documents about social benefits (if applicable)
  4. Pediatrician conclusion (child health certificate)

Children with HIV infection do not need to go to specialized establishments or institutions, and having satisfactory level of health they can go to ordinary children's educational establishments on the equal basis with other children.

The need of children with HIV-infection in special establishments (like sanatorium) can appear just in case when level of health of these children becomes worse and acquires special regimen and medical care.

The children affected by the epidemic of HIV and the children with HIV-infection do not present any danger of infection.

All modes of transmission are known today for certain. Children do not practice risky behavior. That is why there were no cases of HIV transmission from child to child. The assertions about the fact that children often fight and bite one another, and therefore can be infected, are unfounded. Probability of HIV transmission during such situations (which take place rather seldom in particular) occurs just theoretically.

#### **Confidentiality (keeping the secret of diagnosis). Liability of**

The legislation of the Russian Federation defends the secret of diagnosis.

### **officials**

Any official (including the director of educational establishment and the teachers) without parents/guardians consent do not have the right to demand from them obligatory announcement the diagnosis of the child. This law is dedicated to protection of the children and their families from demonstration of stigma and discrimination.

The law stipulates for administrative and criminal responsibility of officials for divulging of the diagnosis «HIV-infection» or private information, which led to negative consequences in life, health (physical and mental) and honor of the child and members of his family.

Unfortunately, in practice the situation is different. If the child was accepted to a children's establishment after all, everybody finds out about his diagnosis very fast: staff (from director to cleaners), parents of other children at this establishment. Often the authorities explain the violation of confidentiality by «concern about safety of other children and staff».

In the situation when there is low awareness of staff and parents about disease, the violation of confidentiality will lead to subjection of the child to high degree of stigmatization: often he is ignored and despised, staff and other pupils are afraid of him, they avoid communication with him. The child begins to feel heavy psychological pressure, he draws into his shell, and he feels like social outcast. All these facts can lead to psycho-emotional and somatic disorders, to psychological and physical developmental retardation. Sometimes the situation can become so complicated because of other parents' negative (sometimes even aggressive) attitude to the child born to an HIV-positive mother, that parents/guardians have to take the child from the establishment.

In this case the child can be protected by competent teacher or psychologist, who has reliable information. He can explain the real situation to his colleagues, parents and children, and he can help to form tolerant and merciful attitude to the children, affected by the epidemic of HIV-infection.

### **Care for an HIV-infected child at a children's educational establishment**

Care for an HIV-infected child almost does not differ from the care for any other child.

In this case teachers at children's educational establishments should be just a little more attentive, caring and sympathetic. It will help to support and strengthen the child's health, also it will promote good development, according to the age.

The state of health of a child (in particular, the necessity to take the antiretroviral medicines) can make the parents tell the teacher about the diagnosis of HIV-infected child voluntarily. Of course, it will happen just if the parents are sure of the teacher, if they consider him competent, conscious and sympathetic person. It is very important in this case that parents and educators become persons holding the same views and partners during the struggle for health and life of the child.

Because of insufficiency of their immune system, HIV-infected

children at children's educational establishments are more amenable to children's catarrhal and other infectious diseases. That is why teachers should always remember, that other children with the symptoms of even slight disease can be real danger for the child with HIV (but not vice versa!). In this situation the teacher should offer to the parents to leave the child with HIV at home until the dangerous period is over.

### **Regimen maintenance**

The accurate maintenance of the regimen of activity and rest is very important for the child with HIV-infection, as for any child.

The child with HIV-infection should have sufficient rest, as all the children of his age. Good sleep in the daytime can help the child to feel cheerful and merry, and gives sufficient strength for games and study.

If the child gets tired soon and often, if he is not attentive, absent-minded, if he has whims and does not cope with study programme, parents should take him to doctor.

Walk in the fresh air is the thing of great importance for normal child's development and health strengthening. The sun and fresh air are also very significant for all the children. Walk in the fresh air improves digestion, activates metabolism, normalizes sleep, and strengthens the organism. The sun light prevents rachitis. Without fresh air children become capricious, weak, have bad sleep and become susceptible to diseases. HIV-infected children should spend enough time in the fresh air. And there is very significant fact – the child should be dressed according to weather conditions and *should not be subject to supercooling or overheating*.

For all the children at kindergarten hygienic procedures are substantial, they keep child's skin and mouth cavity clean. Kindergarten teachers and medical assistants should see to hygienic procedures carrying out and also examine attentively skin and mucous membrane of the children every day. At detection of any skin or mucous membrane lesions – rash, incrustation, diaper rash, pustules, reddening, etc. – the child should be immediately referred to the doctor.

### **Child feeding**

Child feeding is a substantial part of correct care for the child and plays very important role in health maintenance. Child's ration should be balanced with proteins, fats and carbohydrates; it also should contain necessary amount of microelements and vitamins, especially C, D, A, and be caloric enough. If the conditions in kindergarten allow providing the child with necessary ration according to the doctor's prescription, so the staff should discuss all the feeding recommendations with parents/guardians.

If there are not necessary conditions and level of health of the child demands strict adherence to feeding recommendations, it is desirable for the child to stop going to kindergarten.

The children with HIV should take part in games and other activities with other children. Kindergarten teacher should look after these children very attentively and give them an opportunity to have a rest if they are tired. But the HIV-infected children should not be isolated from others.

Child feeding should be balanced, of good quality, and sufficient and correspond to the age of the child. The meal should be cooked just from fresh and quality products.

The appetite of the child should be always encouraged and stimulated.

The eating pattern of an HIV-infected child should coincide with the dietary pattern of other children. But if the child is hungry and asks for food, kindergarten teacher should give him opportunity to «have a bite» - glass of milk, cookies, fruits, etc.

If the child with HIV has bad appetite, he eats little and without desire, he loses his weight, he feels sick, so the urgent consultation by a doctor is acquired. The staff should pay attention to the way of eating and how much food was eaten by the child during one meal. Denial of food can be found as indicator of HIV progression or the appearance of side effects of antiviral therapy. It requires immediate medical intervention.

### **Precautions against water- and food-born infections**

- Uncooked and half-done eggs, dishes which can contain it, raw and half-done meat, meat of birds, fish and other seafood should be expunged from the food ration of an HIV-infected child. All kinds of meat, fish should be well-done.
- Uncooked meat, fish and seafood should not be in contact with other products. For its cooking you should use separate, individual hardboards, knives and other utensils. Hands and kitchen utensils should be washed after the contact with raw products.
- Unpasteurized dairy products should also be expunged from the food ration of the child.
- The water should be boiled for not less than 1 minute. If the child has serious decrease of immunity, so the child should not swim in any body of water, as infection can penetrate into child's organism by accidental swallow.
- Soft and hard cheese, sheep cheese should be removed from the food ration of the HIV-infected child
- Raw fruits and vegetables should be washed carefully before eating; during the period of most evident immunodepression the child should eat only well-cooked fruits and vegetables.
- Bread and products from yeasty pastry should be well-done during severe reduction of immunity.

### **Tempering**

Tempering is one of the factors which are fundamental in prophylactic of children diseases. It improves resistance to unfavorable weather conditions. Following the main principles of

Fundamental principles of tempering are systematization, gradualness and individual approach. Systematization implies constant and continuous carrying out of tempering during the year. Gradualness is gradual adoption from less harsh procedures to more intense manipulations that is prolongation of the time of tempering, water or air temperature drop. Every child, depending on the type of his nervous system, absence or presence of diseases requires individual approach towards conducting tempering.

One of the means of tempering is walking. Walks should take place

tempering, you can prevent the colds.

daily. The total time of being out in the fresh air should be not less than three hours.

Such kind of tempering as rubbing with cold cloth is also very effective. Firstly you should rub the child's skin with dry flannel during two weeks. Rubbing begins with the hands – from fingertips to shoulders, and then feet – from toes to thighs, then chest, belly and the last one is back. Rubbing of each part of the body is performed during 1 – 2 minutes till slight blush. After two weeks you should rub with wet flannel. The flannel is sunk into water and then it is wrung out. Then you should rub in the same way as with dry flannel. First temperature of water during the first rub-down should be 37 degrees centigrade, and then temperature should be dropped to 1-2 degrees every day till 25 degrees centigrade. After cold rubbing of one part of the body, you should immediately rub it energetically with dry towel till slight blush. To increase effectiveness of tempering you can add table salt in water (1 teaspoon of salt per 1 liter).

And one more effective means of tempering is walking on wet salt rug. Salt irritates foot, which has a lot of nerve endings. This treatment tones up peripheric vascular tone. The children undress, living just panties and undershirt. There are three towels on the floor: the first is wet and salty (90 grams per 1 liter of water), the second is just wet, and the third is dry. The foot should be warmed-up, it is very substantial fact. For the attainment of warm-up, you can use gym apparatus with buttons or wooden planks with ribbed surface. The children should walk on the gym apparatus, stamping their feet and rocking themselves to and fro. Then they walk on towel with salt, irritating the warm feet, then they walk on wet towel and rub out salt from their feet; in the end the children dry feet, walking on dry towel.

### **Vaccination of the children with HIV infections**

Vaccination as effective method for HIV-infected child's protection requires special attention because of child's high vulnerability.

Vaccination for children born to HIV-positive mothers and for children with HIV-infection is compulsory prophylactic measure.

HIV infection itself is not the contraindication to vaccination. The only restriction is live vaccine. It is recommended to use only inactivated (killed) vaccine for infections prevention till making a precise diagnosis. In whole, complications of vaccination of HIV-infected children occur not frequently than complications of not infected children. Vaccination of HIV-infected children takes place at common period and in concordance with immunizations schedule accepted in Russia:

- Against hepatitis B – during first days at maternity hospital, then at the age of 1 and of 6 months
- Against poliomyelitis – at the age of 3,4,5 and 6 months
- Against diphtheria, whooping cough, tetanus (diphtheria and tetanus toxoids and pertussis vaccine) – at the age of 3,4,5 and 6 months
- Against measles, parotitis and rubella – at the age of 12-15 months. Mantoux test 2 times per year with the interval of 6

Vaccination of the children born to HIV-positive mothers begins at the maternity hospital and continues at the vaccination room

of the hospital or of child establishment domiciliary.

months

Besides these vaccinations children with HIV-infections should be vaccinated against pneumococcal and meningococcal infections – after turning 2 years old, against influenza – every year (obligatory with inactivated vaccine), against viral hepatitis A (with killed vaccine) according to application instructions.

### **Safety measures during contacts with domestic animals**

It is necessary to remember that some domestic animals, for example, cats can be the source of opportunistic infections, including toxoplasmosis.

If there is a «nature corner» in the childcare establishment, there should not be infected animals. In this case the consultation of a vet doctor is necessary. The animals of this «nature corner» should not go outside, eat raw meat and fish. It is essential to clean toilet for animals.

After the contact with the animal the child should wash the hands with soap. It is necessary to watch over the child that he does not touch the faeces of the animals.

A child should avoid the games with the animals which can lead to scratches and bites. If it is happened, the wound should be washed properly and disinfected (3% solution of hydrogen peroxide, 5% solution of iodine). The animals should not be allowed to lick the wound.

An HIV-infected child should not get into contact with fowl, reptile (lizard, iguana), exotic animals (for example, anthropoid ape), water from aquarium.

### **Restriction of contacts with infected people**

Children with reduced immunity can be easily infected by sick people. It is necessary to limit the communication of an HIV-infected child with people who have acute respiratory diseases.

Even if the child was vaccinated against children's infection, post vaccinal immunity can disappear during the progress of immunodeficiency. And it can lead to infection after the contact with sick person.

### **The role of preschool institution in maintenance of life quality of children with HIV**

The preschool institution can become the first serious «going out». For all children the first visit to the preschool institution can be the stress situation which can have negative impact on the level of health of the child, especially during the adaptation. The first meeting with the new world can be very traumatic for the child with HIV-infections. To this moment the parents, as a rule, try to reduce the time of communication of their child with the environment because they worry about the child's health, and they afraid of the negative attitude

The preschool establishment plays a very important role in formation of tolerant attitude towards children, affected by HIV-infection, and in protection of their rights. The work with the staff and the parents of all children, both infected children and not infected, for informing about HIV, the modes of transmission, safety of communication with HIV-infected children etc., will help to reduce stigma of all people, especially children, thereby to promote the protection and following of children's rights.

of the people around the child. In such situation both the child and parents worry, the child is afraid of unknown conditions, and the parents are anxious about their child.

Benevolent, attentive, professional attitude of the staff of the preschool institution towards a child and his parents can considerably improve the quality of life of children, affected by the epidemic of HIV-infections.

Undoubtedly, the most favorable influence on the child's development is the communication with the peers. The specialists- psychologists, children's psychiatrists and teachers proved the positive effect of the programs of early pedagogic interference. And these programs can be realized at the preschool institutions successfully and professionally.

If the child can go to the preschool institution, the parents can work. Thereby the material welfare of the family becomes better as the quality of life of the child as well. Particularly, the quality of the child's diet becomes better. All these facts create the favorable conditions for the support of child's health.

Professional staff, which is well informed about HIV-infections, can become consultant for the parents. The staff and the parents will be united by the care for the child's health and his development.

Sometimes the staff, because of its professionalism and level of proficiency, can catch alarming signs before parents, and it can attract attention of parents and doctors, that can play decisive role in saving the health of the child, and even his life.

The preschool institution can and even must be the strong link in the system of care, protection and education of children, affected by HIV-infection, and also system of education for adults.

## **Chapter 6**

### **Social abandonment of children born to HIV-positive mothers**

#### **The reasons for social abandonment**

For the last decade the number of abandoned children dramatically increased because of some social and economic reasons.

Even those children, who are not abandoned and live with their families often live in very bad conditions with permanent risk to become factual or social orphans.

Social abandonment among children born to HIV-positive mothers can be caused by several factors, for example, by the level of health and disability of child's mother, which can become worse, and woman will not be able to take care of her child and provide him with all necessary care.

There is another and very widespread example: because of drug or alcohol addiction of the mother the child is brought up by grandparents and other relatives, who can be rather elderly and have the problems with their health, also with money, housing and other problems.

One more example: unfortunately, it is not so rare, when relatives deny care and communication with an HIV-infected child because of unreasonable fear to be infected.

All these facts form direct threat that the child will be cared for by the government.

Multiple-factor problem of social orphanhood will worsen, when HIV-infected mothers abandon their children. As pregnancy and delivery occur in women with depressed immunity, children are very



often born with damaged health. Besides, the children inherit stigma, which is associated with HIV, and it unavoidably leads to prejudiced attitude by all people, who communicate with these children (including their immediate family).

Among the reasons for abandonment of newborn children by their HIV-infected mothers first place is taken by social disadaptation of the mothers, which is connected, as a rule, with alcohol and/or drug abuse. Among the mothers, who abandoned their children, there are women, who had experience of drug abuse and now are in remission phase; they don't have any job and place of abode.

Social, economic and everyday problems (absence of job, steady source of income, domestic and other problems) cause difficulties for the woman, sometimes she is alone, without husband or a partner/father of her child, and she does not see any possibility to bring up her child. Not the least of the factors for abandonment of the child is unformed affection towards the child during pregnancy.

Preventive measures against social abandonment include weakening and elimination of the factors that made a woman to abandon her child.

The reasons for abandonment of the children can be different.

Among general reasons (i.e. unconnected with HIV-infections):

- *Change of social status of a woman* in connection to her pregnancy and child's birth (for example, forced refusal to pursue one's career, impossibility to continue work, etc.)
- *Worsening of financial situation* (impossibility to support one's child)
- *Unavailability of suitable housing conditions*
- *One-parent family* (no father or father's non-participation in upbringing)
- *Social immaturity of a woman* (inability and unwillingness to take responsibility for upbringing and supporting one's child)
- *Drug or alcohol abuse by a woman*
- *Negative models and examples of relations or upbringing in family*, where the woman was raised
- *Other*

The reasons for abandonment of the child, which are connected with HIV-infections, can be following:

- *State of health of a newborn.* Children born to HIV-positive mothers are often born weak, premature, with low-birth-weight. These circumstances frighten the woman and her relatives, who think that such condition of the child "were caused by AIDS". Also there is fear of a baby becoming infected during delivery and fear of his soon death or of his becoming disabled.
- *The situation at maternity obstetric clinics.* For many HIV-

infected women the stay at maternity obstetric service is rather negative experience because of the attitude of medical staff. Biased attitude of medical staff towards HIV-infected women is caused by exaggerated fears of professional exposure HIV, which are rooted in the lack of knowledge about HIV and modes of transmission.

- *Drug abuse.* In some cases women, taking psychotropic substances, during or after delivery can suffer from withdrawal. In this case the woman can leave the maternity hospital to find the drugs before her child will be ready to be discharged from the maternity hospital; so, she leaves the child forever.
- *Financial situation of an HIV-infected woman.* Very often HIV-infected pregnant women are left by their relatives and even father of the child, because of the diagnosis. The situation can be aggravated by lack of formal education, of well-paid legal job, lack or no support of the government or no official registration.
- *Limited access or no access to reliable information and getting medical, social and psychological support.* The facts give evidence that the low level of knowledge about HIV/AIDS and about modes of transmission among wide range of medical and social workers, psychologists and teachers and also among the general public (including HIV-positive mothers and members of their family) causes high level of stigma and, as consequence, discrimination of HIV-infected women and children born to them. Very often specialists are not ready to give the woman reliable information about HIV/AIDS, and it adds more to stereotypes about HIV-positive people, which exist in the society. As a result, the woman carries a child in a very aggressive environment, being subject to severe psychological pressure and reproach.

### **Arrangement of life of abandoned children**

Being at the maternity obstetrics clinic, all abandoned children born to HIV-positive mothers are kept at the special ward for newborn children, the ward at quarantine hospital section.

Nowadays in most cases, after all documents being registered, abandoned children can be transferred to special orphanages for HIV-infected children or into infectious diseases hospitals, or contagious isolation wards of somatic hospitals.

Unfortunately, very often a child has to stay at an infectious diseases hospitals for some weeks and even some months, and sometimes – till the diagnosis is stated (i.e. to 18 months) and even more.

The absence of clear recommendations about arrangement of life of abandoned children born to HIV-positive mothers leads to the situation when such children had to stay at the in-patient department of medico- prophylactic establishments during unreasonably long

period of time. As a rule, the hospitals don't have any opportunity to organize educational work, which is necessary for normal psychomotor development at an early age, as a result the children have irretrievable developmental lag. Such children suffer from deficiency of intellectual, sensory and emotional stimulation, from absence of caress and kindness. The consequences of developmental lag become more serious and more irreversible with child's growth. Some children live in isolation for such a long time, that they acquire, as some observers say, "the syndrome of Mowgli". A lot of children who live at hospitals and wait for the detection of their HIV-status, cannot speak, walk, sit at the table, and eat with spoon, while their peers do this without any difficulty. *All these phenomena are not connected directly to HIV-infection, but they are the consequences of lack of communication with adults and peers.*

Many specialists (doctors, teachers and psychologists) and official establishment consider such situation as unacceptable. In some regions of the Russian Federation doctors, regional authorities and public organizations make efforts to make the stay of the children at hospitals not so joyless. In such hospitals psychologists and teachers work, game rooms and playgrounds are built, the children are supplied with supplementary food products etc. The example can be children's Centre "Aistyonok" ("Little Stork"), which is a part of the infectious diseases hospital de jure, but children's medico-socio-educational establishment de facto. The experience of children's centre "Little Stork" is represented in Appendix 3, as real and rather successful model of arrangement of life of abandoned children from the first days of their life.

If HIV-infection was not detected, the children should be sent to common type children's houses.

However authorities of common type orphanages often refuse to accept the children with HIV-infection and with unstated diagnosis.

Refusing to accept the child born to HIV-positive mother, the authorities of common type orphanages advance different arguments, including such as: abandoned child is transferred from medico-prophylactic establishment of another region; they refer to the absence of some documents (birth certificate, official document about abandonment, warranted Russian citizenship, etc.); necessity and at the same time impossibility of organizing "special" conditions to support these children.

But the first and the main reason for refusal to accept the child with perinatal contact (i.e. born to HIV-positive mother) at the common type children's establishment is absolutely groundless fear, that the children born to HIV-positive mothers can be the source of infection for the children staying here and for the staff. These fears are connected in most of the cases to the absence of required and reliable information about HIV/AIDS.

Adoption of Law № 299 dated June 3, 2003 of the Ministry of Health of the Russian Federation "About universal nomenclature of state and municipal healthcare establishments" opened the opportunity for creation of specialized children's establishments for HIV-infected children and children born to HIV-positive mothers (before their removal from regular medical check-up in connection to the absence

Nowadays all abandoned children with perinatal HIV-contact or HIV-positive children, if there aren't any medical contraindications, should be placed at the common type children's houses, according their age and development.

of HIV-infection). Being governed by the law, in some areas the common type orphanages were restructured to become specialized establishments for HIV-infected children. At some areas with a big number of abandoned children with perinatal contact the specialized establishments were organized before adopting that law.

This arrangement allows transferring dozens of abandoned children, who spent months and years at hospitals (more often at infectious disease hospitals or contagious isolation wards), to establishments, where the children obtain the possibility to communicate and play with peers and kindergarten teachers, that undoubtedly promote children's development.

But because of limited number of places available at specialized children's establishments, not all abandoned children can be accepted, and some part of the children stay at medico-prophylactic establishments.

Besides, creation of specialized children's establishments for HIV-infected children promotes consolidation in public conscience of incorrect idea, that the children born to HIV-positive mothers should be isolated from the other children. But the creation of specialized children's establishments took place, first of all, because of necessity to take care after HIV-infected children (and not because of the fear to spread the infection at the common type orphanages) in conditions of qualified systematic medical supervision and of guarding the children from display of stigma and discrimination.

### **Arrangement the children in families**

Nowadays we can hardly find specialists-teachers, psychologists, pediatricians, who defend advantages of orphanages over upbringing in families. Children who were brought up at orphanages commit crimes, become unemployed, lose their dwelling, take drugs and alcohol, and also commit suicide more often than the children, who were brought up in families.

According to specialists from the Ministry of Education, a typical child from an orphanage has such characteristics: "backward social intellect, dependency, increased suggestibility, overestimated or very low self-appraisal, inadequacy of pretensions, lack of understanding of material level of life, of the notion of ownership, readiness to accept asocial behavior patterns". In the light of this conclusion such problems as low level of arrangement of the children born to HIV-positive mothers in the families and their prolonged staying at hospitals become more acute.

Russian legislation does not prevent adoption of abandoned children born to HIV-positive mothers and orphans with HIV-infections. But such children are adopted very seldom. The main obstacles for adoption the children born to HIV-positive mothers or HIV-infected children are:

- Prejudice of people against the children affected by HIV/AIDS
- Undetermined HIV-status of the child for a long time (see Chapter 1, Section "Laboratory diagnostics of HIV-infection in children born to HIV-positive mothers")

- Mental and physical retardation of children because of long staying at hospitals
- Skeptical and preconceived opinion of the workers in the sphere of adoption about the children born to HIV-positive mothers or HIV-infected children
- Fears among adopting parents concerning peculiarities of the care for HIV-infected children

These factors make the child affected by HIV/AIDS epidemic “less attractive” in the eyes of prospective adoptive parents, and as a result, such children have very small chances to be adopted.

According to recent studies and analytical publications of some leading experts on childhood protection the perspectives of expansion of such forms of family arrangement as adopting and patronage families seem more optimistic for the children born to HIV-positive mothers or HIV-infected children. Adopting and patronage parents are the “parents-professionals”, who work for orphanages. At some regions of the country the idea of “professional family” is worked out very actively and it is implemented as a base for the new model of orphanages arrangement. First attempts to arrange HIV-infected children at such families were made (for example, in Kaliningrad and Moscow).

## **Chapter 7**

### **Rights and Duties of HIV-positive People. Protection of the rights of the child.**

HIV-positive citizens who live in the Russian Federation have all rights on its territory and perform duties in accordance to the Constitution and Legislation.

All people who are infected with HIV/AIDS, being citizens of their country, and first of all children are protected by law. The knowledge of laws helps people affected by the epidemic of HIV/AIDS, specialists and executive workers to protect their rights and to execute their duty in a proper manner and also avoid some problems.

The main document in the sphere of regulation of HIV/AIDS is Federal Law which was brought in March 30, 1995, № 38-FL “About Prevention of Spread on the territory of the Russian Federation of a disease, called Human Immunodeficiency Virus (HIV-infection)” (further – HIV Law). It is implemented starting January 1, 2005 and is stated in the Federal Law dated August 22, 2004 № 122 –FL. The law contains guarantees that people’s rights will be maintained. It also states responsibilities of the government to prevent and treat the disease, provide social support to workers who are at risk of being infected by the virus.

#### **Medical examination**

In accordance with general rules (Article № 8 of HIV law) medical examination should be carried out voluntary – upon request or with consent of a person. Children can be examined with the consent of their parents or their legal representative. HIV examination may be

carried out anonymously. Medical examination, including appropriate laboratory examination is fulfilled at a state, municipal or private medical centers which managed to get an appropriate license to carry out such kind of activity. The examination should be followed up by a preliminary and subsequent counseling. At state medical centers examination is fulfilled free of charge (Article №7). In the initial version of the law that had been effective until January 1, 2005, free examination could be accomplished at municipal medical centers. In the effective version of the law, either paid or free procedures at medical centers, which are subordinate to the outpatient departments, will be determined on the local level subject to the possibilities of municipal centers.

### **People who are subject to compulsory examination**

- blood, biological (body) fluids, organs and tissue donors;
- workers of certain professions, at factories, enterprises, institution and organization (this list was approved by order of the Ministry of Public Health and medical industry of the Russian Federation № 295 dated October 30, 1995);
- people who live at the institutions of confinement (inmates). According to the rules approved by The Government of the Russian Federation;
- foreign citizens and people without citizenship who arrive in Russia for a period of more than 3 months, except for attachés and consular office workers of foreign countries, international intergovernmental organization workers and member of their families (Article № 10);
- men enlisted in the Army and involved into military service by the contract (obligation is determined by the regulation of military-medical examination, approved by the Governmental Regulation of the Russian Federation dated February 25, 2003, №123).

In respect of other categories of citizens, including pregnant women, sick men with clinical signs and also by the job interview offered by employers (if a corresponding profession and organization are not included in the list approved by Enactment № 877 ) medical examination can be carried out voluntarily;

Medical examination of adolescents at the age of 14 and younger and incapable people may be carried out upon the request or by the agreement of their legal representatives, tutors who have a right to be present during the medical testing.

Health workers are obliged to inform a person about his/her results of the examination. In case of detection of HIV-infection among adolescents under the age 18 or incapable people, the appropriate information should be provided to their parents or to their legal representatives (Article №13 of HIV Law).

### **Maintenance of Medical Secrecy**

Diagnosis “HIV-infection” as well as other secret information about

the health condition of a person should be considered as the medical secrecy. There are lists of cases when medical workers may provide the third parties with the information that is considered to be the medical secrecy, without the agreement of an examined person, is established by Article № 61 of the Basics of Law System of the Russian Federation about Guardianship of citizens' health. There are five cases:

“Medical workers and other people who perform their service and professional duties can find out the results of HIV examination obliged to keep this information in secret. People who disclose information which is the medical secrecy in connection to the performance of their service and professional duties bear responsibility in accordance to the legislation of the Russian Federation”.

1. for the purpose of examination and treatment of a citizen who cannot express his will because of his health condition;
2. in case of the dissemination of infectious diseases, mass poisoning and affect;
3. on demand of the Department of Questioning and Investigation, of a prosecutor and a judge in connection with holding of an inquiry or a trial;
4. in case of providing aid to an adolescent at the age under 18 to inform his parents or legal representatives;
5. if there are some grounds which make it possible to suppose that the harm was done in the result of unlawful acts.

All information about an HIV-infected person is ultra-confidential and should not be disclosed without the agreement of this person or his guardian (legal representative).

#### **Responsibility for infecting and for exposing to danger of HIV infection**

Article № 122 of the Criminal Code of the Russian Federation (“Infecting with HIV”) establishes responsibility for known actions of a person who knew about his status:

- for known HIV-infection endangering of another person (version of the original document);
- infecting of another person with HIV by a person who knew that he had an infection.

But there is a problem connected to evidence of known HIV-infection endangering (version of the criminal code) of the other person as well as the fact of HIV infecting. It is difficult to say whether the HIV-positive partner knew about his diagnosis and whether he infected another one purposely.

On the other hand this problem arises in the case when it is necessary to avoid criminal responsibility.

The Federal Law which was brought on December 8, 2003 № 163 FL adds this article with some notes in accordance with which a person who endangered or infected another one can be freed from criminal responsibility “in the case if another person knew that his partner is HIV infected and agreed to act voluntary” (the original document version).

This addition frees HIV-infected people from punishment which hangs over a married couple if one spouse is HIV-infected but another one is not.

### **Refusal to help to a HIV-infected person**

All kinds of medical aid should be rendered to all HIV-infected people in accordance with clinical examination.

Article №14 of HIV Law comprises nondiscrimination guarantees of HIV-infected people during the medical services: “HIV-infected people can get any kind of medical aid without special preferences; alongside with it they have the rights which are provided by the Legislation about health protection”.

Doctor’s refusal to help can be regarded as the criminal offence according to Article №124 of the Criminal Code: “Refusal to help an HIV-infected person without reasonable excuse by a person who is obliged to give such help, which later led to causing medium damage to health of the patient, should be punished by a fine of 40,000 rubles or a salary of this doctor for a period of three months, or punished by correctional works for a period of up to one year, or arrest for a period from 2 to 4 months.

In case of rejecting, if these actions do not suit to Article № 124 of The Criminal Code, a doctor can be brought to the disciplinary liability in accordance with the Labor Code of the Russian Federation.

### **Rights of HIV-positive people and their families members**

HIV-positive people have following rights:

- to get information about the results of their medical examination in written form;
- to unprejudiced attitude;
- to keeping the medical secrecy, except for the cases which are approved by the legislation;
- to continue job performance, except for the cases which are approved by the Russian Federation Government;
- to get doctor's consultation in order to get acquainted with prevention activities against spread of HIV infection.

HIV-infected people cannot be the subjects for scientific experiments and examinations without their written consent.

### **Rights of HIV-infected children and their parents (legal representatives)**

HIV-infected non-adult people under the age 18 are granted a public pension, benefit.

HIV-infected children under the age of 16 and their parents or legal representatives have the rights approved by legislation for disabled children under the age of 16.

For instance, parents (legal representatives) of an HIV-infected child have rights:

- to be together with children under the age 15 at hospital establishment with a benefit payment according to the social insurance;
- to maintain continuous service record of one parent or the other legal representative of a HIV-infected child under the age 18, in case of dismissal in order to take care of a child and on the assumption of coming back to work until the child will



be 18;

- to include the time of taking care after the HIV-infected child in the general service record;
- to get benefit payment for taking care for an HIV-infected child.

### **Social protection of HIV-infected people and their family members**

The violation of Federal Law “About prevention of spreading within the Russian Federation of the disease, called human immunodeficiency virus (HIV-infection)” involves disciplinary, criminal and civil responsibility.

If HIV-infection is found, in accordance to the above mentioned Federal Law, the following cases are not allowed:

- dismissal;
- rejection in giving access to educational and medical establishments;
- limitation of rights and legitimate interest of HIV-infected people and their family members.

## **Chapter 8**

### **Stigma and Discrimination**

#### **Definition of a conceptual framework and basis of activity: stigma and discrimination in connection to HIV/AIDS, September 2002**

Stigma and discrimination connected to HIV/AIDS are the main obstacle for infection prevention, proper care, support and treatment and relief of the consequences of the epidemic.

Stigma and discrimination which are connected to HIV/AIDS may be considered as a worldwide phenomenon, people can face them in every country and every part of the world. The reasons of their origin can be different – misunderstanding of diseases, myths about HIV transmission, prejudices, lack of medical treatment, irresponsible information about epidemic in Mass Media, the fact that AIDS cannot be cured, widespread fears in the society connected with sexuality, disease and death; fears connected with illegal drug and injection drug abuse.

All over the world shame and stigma, connected to the epidemic, do not allow debate publicly about the reasons of its origin and the necessary plan of action. For that reason HIV-infected people and people affected by the epidemic experience guilt and shame, they cannot express their opinion and are afraid that their problems will not be taken seriously. In this connection, politicians and policy makers deny the fact that such problem exists and that it is necessary to take urgent measures.

Stigma and discrimination connected to HIV/AIDS have other consequences. Particularly, they have psychological effect upon HIV/AIDS-infected people self-consciousness, in some cases it causes depression, low self-esteem, despair. They decline prophylaxis because they are afraid of people awareness whether they are infected

or not.

### **Stigma**

Stigma – is the process of a person depreciation.

The definition of stigma can be traced back to high antiquity. In Ancient Greece the word “stigma” meant a mark on a slave body or a criminal. Nowadays stigma is a prejudged, negative attitude to a person or a group of people in connection to their distinctive features. Stigma – a characteristics of a person (color of skin, manner of talking, deeds, etc.), which “greatly discredits” him/her in the eyes of people around. Stigma greatly influences the sense of self-being. Stigmatization is a process of personal devaluation.

In most cases HIV/AIDS stigma develops on the ground of emerged negative ideas and strengthens them. It is often said that HIV/AIDS-infected people deserved it by their actions. Often such “bad behavior” connected with sex or with forbidden or socially damnable actions such as injection drug abuse.

In the end, stigma develops social inequality. It is the reason for some groups of people to be considered unworthy, while others feel superiority.

All HIV-infected men are said to be – homosexuals, bisexuals or men who visit commercial sex workers. All HIV-infected women have sexual promiscuity or they work in sex-business. Often family and society develop stigma and discrimination because of the fear, partly because of ignorance and more often it is easier to find guilt with those who were infected first.

Stigmatization can be reason for depressions, shrinking into oneself and inferiority complex. It undermines and exhausts already depressed people, it makes people blame themselves for being in such bad situation.

### **Discrimination**

Discrimination is the limitation of rights and freedom.

Because of HIV/AIDS stigma discrimination appears, and the rights of HIV/AIDS-infected people and their families are usually violated. Violation of human rights strengthens the epidemic consequences. For example, it provokes excessive anxiety and sufferings on the personal level in its turn these factors lead to health deterioration. On the family level it makes feel guilt, people conceal the fact of infection and reject participating in positive retaliation activities. On the society level, discrimination of HIV-infected people strengthens false idea about such activities and that HIV-infected people can be rejected and condemned.

Human rights are the inalienable factor of a person existence and these rights cover all humanity. The non-discrimination principle takes the central place in the theory and right practice of a person.

Freedom from discrimination is one of the main rights of a person which are based on general and eternal right principles. The main international laws about the human rights prohibit discrimination by race, color of skin, sex, language, by religious and political beliefs, by national and social origin, by property and birth status or by the other status. In resolution of United Nation Committee on Human Rights is proclaimed that the term “the other status” should be interpreted as the health state including HIV/AIDS.

In order to provide effective activities according to stigma and discrimination resistance in connection to HIV/AIDS, the work should be done in several directions at the same time: information and

enlightenment for the best understanding of the problem, actions which can form fair political conditions, usage of legal techniques where they are necessary in order to bring to account the government, employers, establishments, and some people.

### **Stigma and Discrimination research concerning HIV-infected People in Irkutsk City**

In the end of 2005 in Irkutsk upon demand from the Russian Red Cross a special research was conducted within the frames of Project “Adults decide the fate of children”. The first goal was to reveal and analyze difficulties which every family with HIV-infected children faces when trying to place their children into a kindergarten; the second was to reveal the reasons of non-tolerant attitude from the kindergarten personnel and of the parents of other children.

The subject for the research was three groups of respondents who live Irkutsk City:

- members of 20 families, where HIV-infected preschool children live;
- parents of other preschool children who attend kindergarten (20 people);
- kindergarten personnel.

The results of the research showed that the problem of registering a child at a kindergarten is rather urgent in Irkutsk. However not all the participants of the research had a positive experience concerning this problem:

...none of the participants of the research informed that his child attends a kindergarten;

...only 4 out of 20 respondents mentioned that they had not begun the preparation of the documents or they are on the waiting list for a kindergarten and do not know what situation they will face with;

...practically all 20 participants faced the problem of registering a child at a kindergarten and his further attendance there.

Also parents who bring up an HIV-infected child already faced some negative moments:

- disclosure of diagnosis by medical personnel, refusal to document preparation necessary for registering a child to a kindergarten;
- refusal by the personnel of the kindergarten to register a child;
- unfavorable and aggressive attitude of other parents;
- high fee for f kindergarten;
- long waiting list for attending a kindergarten;
- absence and/or lack of awareness and practice of defending children’s rights;
- lack of interest in placing a child to a kindergarten.

Judging by the results of the research, among the members of families who bring up an HIV-infected child, parents attitude forms out of:

- personal experience (conflicts connected with stigma and discrimination when parents try to place their children to a kindergarten);
- awareness about HIV/AIDS (some peculiarities of infection course in children, modes of transmission and prevention/safety precautions);
- absence and/or lack of awareness about children's rights;
- practice of assertion children's rights;
- widespread stereotypes of attitude towards HIV-infected children in our society and among separate groups of people.

Often the parents of HIV-infected children notice that the occurrence of stigma and discrimination appears among medical workers: this is the case of diagnosis disclosure, including some notes in the documents of a child including a medical card; rejection to render medical aid; preconceived attitude among medical workers; lack of knowledge about preventive measures by a pediatrician and skills to work with HIV-positive children.

Judging by the answers of other children's parents, it is possible to say that most of the parents think that HIV-infected children should attend other (maybe specialized) kindergartens because of possible HIV transmission through the contact of children with each other.

This attitude can be formed under some reasons:

First, the level of awareness is rather low, especially awareness about the ways of virus transmission and also HIV occurrence among various strata of the society.

Second, the theme about HIV/AIDS is interpreted as the problem of separate or often a marginal group of population such as drug users or sex-workers. In this group view, the other ways of transmission are the rare exception, for instance, when transmission occurs by cuts, injuries, blood transfusions at medical establishments. There is no a definite opinion about safe sex. There are widespread ideas that official marriage and a long-lasting sexual relationship with one partner are the guarantees of protection.

Third, parents strive to make their children safe against possible risks and dangers; that is why even a minimal probability of infection is taken as a real health hazard and a danger to life of their children.

The similar situation is observed among the personnel at child care institutions. The opinions of the kindergarten personnel let underline some stereotypes in the understanding of HIV/AIDS.

First, stereotypes of the need in special medical care after HIV-infected children.

Second, understanding that HIV/AIDS problem is the problem concerning exclusively the marginal groups of people ("drug users", or those "people who change their sexual partners too often", then "who do not pay attention to the appearance of their partners", "irregular sexual contacts" and "disadvantaged families" and so on).

Third, stereotypes in respect to taking an HIV-positive (a child or an adult) as aggressive and inadequate with other people.

On the whole it is possible to say that kindergarten personnel do not have a definite attitude towards the attendance of HIV-infected children on the common grounds. According to the opinion of survey participants, kindergarten personnel have negative attitude towards the attendance of HIV-infected children.

It is connected to a number of reasons:

- modern organization of educational process in kindergartens,

It becomes more and more urgent to set up a system for prevention and education activities for parents of HIV-positive and HIV-negative children, personnel at kindergartens, medical workers at healthcare establishments, as well as providing social, counseling and legal support to parents and guardians of children living with HIV/AIDS. This will allow to eliminate the existing barriers that HIV-positive children face when trying to register at educational establishments on the equal basis.

“Some children were born with immunodeficiency virus. Like other children they need warmth and care from adults. Children should play, communicate and be friends with their peers. Immunodeficiency virus is not transmit through saliva, tears, skin, breath, handshaking, common dishes. HIV is not dangerous in everyday communication.”

Eugene Voronin,  
Professor, Doctor of Medicine,  
director of theoretical and  
practical Center of the Ministry of  
Public Health of the RF “Help to  
pregnant women and HIV-  
infected children”, has been  
treating HIV-positive children for  
more than 15 years.”

personnel say that it is impossible to keep an eye on all the children;

- kindergarten personnel do not possess reliable and full information about HIV/AIDS and about care and methods which are necessary for an HIV-infected child;
- personnel fears for their own and other children health and for HIV-infected children;
- kindergarten personnel does not possess the information about the rights of HIV-infected children;
- there is a false stereotype concerning the risk of HIV/AIDS infection and what affect HIV has on a person’s organism especially on his nervous system (adequacy of perception and behavior).

Medical research at the AIDS Center, feedback from HIV-positive clients of the Red Cross and the data of survey show that the Russian legislation guarantees children the right of attendance of a kindergarten on the common basis with other children. Most families who bring up an HIV-positive child do not want their children to attend a kindergarten.

There are many reasons why a child does not attend a kindergarten: absence of documents and medical certificates, poor immunity of a child, fear of infection of other children, negative attitude of personnel or other parents, necessity to disclose HIV-status of a child, necessity to control taking the medicine and so on. Though the majority of these reasons are not substantial enough to deprive a child of using the services of a kindergarten and of the opportunity to develop fully.

### **Conclusion**

Children are the biggest humanity value, its hope and meaning of life. But children at the same time are the most vulnerable and defenseless part of the humanity. People should care for and protect our children without any doubt.

Today one more group of children appeared in our world which demands care, attention and love – these are HIV-infected children. They will get a good profession, some of them will be scientists, prominent writers and artists, geniuses and just good hard-working people on whom our society based and will base. And only adults are able to provide our children with long-lasting and happy life.

## **Appendix №1**

### **Guidelines on conducting an antiretroviral therapy in children**

#### **Medicine preparation for a day**

An integral component of child aid is discussion of medicine preparation with a child caregiver. A special circle of caregivers should be chosen for medicine preparation. All of them should have some practical skills. Instruction should be given again in full volume if a dosage, medicine or caregivers change.

1. Instructor (medical worker – a doctor or a nurse) should show pills, capsules or liquid forms of medicines to the caregivers and teach how to prepare them:
  - For pills and capsules – it is necessary to ask a caregiver to fill a container with dose of the medicines for taking during a day (after demonstration by the instructor).
  - For liquid drugs – to fill a syringe with the liquid medicine for taking during a day.
2. It is necessary to think up a marking for the medicines which look like outward and it is better to mark them with many-colored tags. Instruction of the medicine marking should be noticeable and accessible. It is necessary to mark a syringe or vial with the color which is marked on the original bottle of the medicine.
3. Caregivers should prepare medicine in a quiet manner and without rush. It is very important during first weeks of treatment. Child care institutions management should allot time for care-givers for medicine preparation and a special place.
4. It is necessary for a child to take the medicines strictly on time which should be written as an instruction and be placed in an accessible or noticeable place.

#### **Dosage of liquid medicines**

Medicine dosage for children should be exact in order to keep medicine concentration in blood.

- 1 It is necessary to use syringes for liquid medicines. Do not measure medicine by a spoon because they differ in size and that is why the dosage will be inexact.
2. Syringes must be marked with the colored adhesive tape by the level of necessary dosage (a vial with the medicine and a syringe for this medicine must be marked with one color).
3. A separate syringe should be used for a definite medicine; the drug should not be kept in the syringe – after filling the syringe with the medicine, the medicine should be used according to its purpose (i.e. a dose of liquid medicine should be measured by a syringe before injection).
4. Syringes may be used many times until a marking does not erase, an adhesive tape does not unstuck and a syringe piston does not get stuck; after usage the syringe should be washed in warm soap water, rinsed out thoroughly and aired. Syringes must be kept in a clean closed houseware.
5. From time to time caregivers should practice how to fill syringes with the necessary medicine doses and also to discuss such important questions as what to do if a medicine is too thick and was spilled.

#### **Medicine storage**

It is better to store the medicines at a low temperature. Medicines should not be kept in the sun and in hot places. Most antiretroviral drugs must be kept in cool places (for example, in a refrigerator). Liquid medicine must be kept in a glassware because some medicines erode plastic.

*It is important to remember that all the medicine should be kept in an inaccessible place for children! Never call the medicine “candy” in order to avert a goal seek and taking the medicine out of control.*

### **How to avoid unpleasant medicine taste**

Not all drugs have unpleasant taste but if a drug is unpalatable it is difficult to make a child take it. It would be wise to carry out “gustative test” before an antiviral therapy: every child should taste those drugs which they take everyday. If taste of a definite medicine is disgusting for a child, it is necessary to calm him/her down and think over how to hide or reduce the unpleasant taste and find a special way of taking the medicine which can satisfy a child.

1. For liquid drugs: first fill a syringe with a medicine in order to measure the dose, then add in the medicine something sweet about 5-10 milliliter – juice, milk or children’s drink, shake it thoroughly (do not mix medicines with too much of other liquids). It is necessary to see whether a child drank mixture till the end.
2. Other methods: dip the syringe tip in something sweet in order to change taste or a child should drink something sweet before taking the medicine and after it.
3. For pills: grind a pill to powder with the help of a mortar and mallet. For capsules: open a capsule and pour its contents in a small cup. Add to the medicine 1-2 teaspoon of jam, preserve, squashed banana or macerated in milk cereal then shake it thoroughly. Feed it to a child till the end just to be sure that the dose was taken.
4. Caregivers should talk over to an older child the possibility to swallow pills broken in two. Hard pills can be dipped in something viscous because it will be easy to swallow them.
5. After taking the medicine give a child something sweet. Sweet or spicy food also helps before taking medicine.
6. Do not forget to praise a child after taking each dose of medicine.

### **Efforts to avoid nausea**

Be curious whether a medicine causes nausea because nausea is a serious obstacle for treatment.

If medicines cause nausea:

1. Give a child a little unflavored food (cereals, cracker, bread), then give a child a medicine.
2. Let a child take a little water or other drink with pills and capsules. Children are tending to drink more water than it is necessary, big amount of water causes nausea.
3. It is necessary to remember that nausea is a temporary phenomenon. It will pass when a children’s organism get used to medicine.
4. Give medicine to a child without rush especially during first weeks of treatment.

### **Special cases**

If a child resists constantly and sometimes refuses to take medicine, caregivers can work out a system of encouragements. It is useful to start a calendar for preschool children and draw there a funny face or other sign when a child takes medicine obediently. When a definite amount of funny faces will be amassed, a child can receive a gift. Little children acquire more attention, patient care and endearment. Praise your child after each dose of the medicine, pat him on the head, take him in your arms, and talk to him tenderly. Give your child something tasty after taking the medicine.

## Appendix № 2

### Development periods of motor and mental skills of children

Smile	5 weeks (3 - 8 weeks)
Booming	2 weeks (4 - 11 weeks)
Holding its head	2 months (1.5 – 3 months)
Purposeful hand moving	4 months (2.5 – 5.5 months)
Turning	5 months (3.5 – 6.5 months)
Sitting	6 months (5.5 – 8 months)
Crawling	7 months (5 – 9 months)
Accidental snatching	8 months (5.5 – 10.5 months)
Getting up	9 months (6 – 11 months)
Steps with a prop	9.5 months (6.5 – 12.5 months)
Unassisted standing	10.5 months (8 – 13 months)
Unassisted walking	12 months (9 – 14 months)

### Development periods of vocal responses and speech

1.5 months	booming
4 months	“reed pipe”
7 – 8.5 months	babble: pronounces syllables
8.5 – 9.5 months	repeats syllables with different intonation
9.5 – 18 months	pronounces short words, imitates sounds, all words in nominative case, singular
18 – 20 months	tries to pronounce two words in a phrase. Appear imperative mood of verbs (Give me!)
20 – 22 months	appear plural forms of words
22 – 24 months	vocabulary reaches 300 words. From 18 to 24 months – the first period of questions “What is it?”
3 years	vocabulary increases: usage of long monologs
4- 5 years	the second period of questions “Why?”

### Rate of Mental Development of Children at the age of 2 years

Activity	1,3 years old	1,6 years old
Sensory development	During a game he differs the objects by their size	He can choose an object of the same shape out of the object of different shape by the model and a word.
Moving	Goes for a long time, changes his position (squats, bends)	Oversteps over obstacles with one step
Game, object manipulation	Can make learned actions by the game (puts together a pyramid)	Can repeat some actions
Active speech	Uses babble and simple words	Can name an object in time of astonishment, happiness or strong impression
Speech	Sustainably increases the	Can find two similar object among others but



understanding	vocabulary	different in color and size.
Habits	Can eat by himself thick food with the help of a spoon	Can eat by himself liquid food with the help of a spoon

### Rate of Mental Development of Children at the age of 2 years (continuation)

Activity	1,9 years old	2 years old
Sensory development	During a game he differs the objects by their size	Can find an object of the same color if an adult asks him
Moving	Can go on the surface with the width of 15-20 cm and at the height of 15-20 cm above the floor	Oversteps over obstacles with interchanging steps
Game, object manipulation	Builds gates, a bench, a house	Can produce logically connected actions during the game
Active speech	Uses two-word sentences	Uses long and two-word sentences by the communication with adults
Speech understanding	Answers questions by the understanding of a story with plot	Understands a short story with familiar situations
Habits	Partly can take off his clothes with a small help of an adult	Partly can put on with a small help of an adult

### Rate of Mental Development of Children at the age of 3 years

Activity	2,6 years old	3 years old
Sensory development	Chooses by the model different objects of 4 colors (red, blue, yellow, green)	Names for main colors
Moving	Oversteps over several obstacles, lying on the floor at the distance among them about 20 cm	Oversteps over obstacles with the height about 10-15 cm
Game, object manipulation	By the games acts interrelated and logically	Play roles in games
Active speech	Builds sentences with 3 and more words	Uses composite sentences
Habits	Can put on by himself but cannot button up and lace up his shoes	Can put on by himself but with the help of adults can button up and lace his shoes

### **Appendix № 3**

#### **Peculiarities of Socialization of abandoned HIV-infected Children at Irkutsk Center “Little Stork”**

Here you will find information about experience of socialization of abandoned children born by HIV-positive mothers in Irkutsk at a municipal (now regional) infectious diseases hospital.

Necessary explanations:

*Presented below is the model of life of abandoned children, who were born by HIV-positive mothers. This model was used from 2002 till the end of 2006 and was found rather successful by many specialists.*

*Today Center “Little Stork” does not exist. Starting November 2006 all “neglected” children, born to HIV-positive mothers in Irkutsk region, sent to Children’s Nursing Houses and orphanages after discharge from the maternity department.*

*“Little Stork” does not exist anymore but experience of this center is unique and important. The model of life of children at Center “Little Stork” certainly cannot be considered as ideal and “the right” one. But this mode proved one more time that early pedagogical interference, care and attention for a child can improve his physical and mental development and also the quality of life of abandoned children. This mode demonstrated that in any case one can find the ways and means to act in the interests of children.*

*We hope that the work experience with HIV-infected children of the personnel at the regional infectious diseases hospital in Irkutsk can be useful for personnel of any child care institution and can be used with success for improving physical and mental development of all children without exceptions.*

Varnakova Rosa Dorzheivna,  
In 2002-2006 Director of Ward № 3 at  
the Infectious Diseases Hospital  
(Center “Little Stork”)

In complicated socially-political conditions of the modern society, the children orphanhood causes profound worries among doctors, psychologists and teachers, as these children are found in socially dangerous situation.

Abnormal forms of maternal behavior is the rejection of her own child as a result of alcoholism, drug abuse etc, it is the reason that the biggest part of neglected children inherit addiction and suffer from innate mental and physical pathology. Early separation with mother causes a child to develop deprivation mental disorders, with especially vulnerable being the emotionally-volitional and cognitive spheres.

The situation often worsens because neglected children, born to HIV-positive mothers, stay for a long time (several months and even years) at in-patient departments first at a maternity department and after that at an infectious diseases hospital.

For children, born to HIV-infected parents, “Little Stork” Center was established in Irkutsk, for treatment of children and rehabilitation; the Center worked from 2002 till 2006. In reality, Center “Little Stork” is the children's ward № 3 at municipal infectious diseases hospital in Irkutsk which was specially staffed with teachers and medical workers that allowed to set up a medically-pedagogical establishment for children born to HIV-infected mothers. The main task of medical and pedagogical personnel of Center “Little Stork” was – to ensure trouble-free adaptation to the social world, to maintain health condition and the quality of life of abandoned children, born to HIV-positive mothers and life of HIV-infected children.

Socialization – is the process of the modification from infancy of an individual's behaviour to conform with the demands of social life. This process is rather difficult for children from well-to-do families, but it is especially difficult for children who live at orphanages.

The surrounding world of things, nature, adults and peers and relationships between them influences on the child's socialization. It is necessary to possess the technology, based on theoretical and practical knowledge in order to influence positively the child's socialization. The medical and pedagogical personnel of Center "Little Stork" acquire such knowledge at specially organized seminars and medical-pedagogical conferences in order to obtain the unity of health-improving and educational work in solving the assigned task:

1. to show children an adequate notion about the social world and about themselves, to foster in children the feeling of goodness, love and trust.
2. to use the methods which favor the development of cognition and behaviour of a child during the acquaintance with the social life, to set up the pedagogical process taking into account the chief activity status.

It is necessary to set up the chief activity status at every age periods that favor normal physical and neurologic-and-mental development.

The first year of life – is communication of a child with an adult. During the communication, emotionally-individual relationships the cognitive process (sensation, perception, imagination, thinking and speech) develops.

A very quick rate of physical and neurologic-and-mental development of the children's first year and constantly increasing needs shows the personnel the necessity of timely arranging a best performance and competent methods of some time regimes (sleep, feeding, water closet). Children live according to four regimes where the feeding, sleep and awake state rhythms are determined taking into account the age.

Children's socialization of first year the subject-developing environment plays an important role with thorough selection of didactic and playing material which changes every 4-5 times at the period of wakeful state of a child. Systematic game-lessons established by nurses and teachers favor emotional and mental development of children. Teaching of the leading, basic skills is taken into account: under the age of 3 months – is the "enlivening complex", at the age of 3-5 or 6 months – overturning from the back on the stomach and vice-versa, from 6 till 9, 10 months – booming, babble, snatching, scrawling; from 10 months till year – unassisted walking, purposeful actions with objects, active vocabulary of 10 words. Late development of the leading skills due to lack of communication with adults leads to a phenomenon called "hospitalism" (retardation of physical and neuropsychic development) several children from "Little Stork" suffer from it. The personnel knows that during teaching a child it is necessary to see the "area of next development" – skills which a child can do by himself, and the "area of today development" – skills which a child should learn in proper time (L.S. Vigotskiy). But nurses and educators spend much time carrying out the regime processes, hygienic care while the things that should be done concerning children care should not be more important then the children by themselves.

That is why the first year of life of a child is important for the optimal socialization if there is a comfortable environment, arranged by the personnel and attentive maternal care and good attitude to children. All these things taken together help most of children at the Center "Stork" to get accustomed without troubles to the social world.

Teaching process for children at the age of 2 to 5 years is formed on the humanity, therapeutic grounds taking into account the leading object-playing activity.

Health and physical development promotion can be carried out with the help of massage, outdoor games, morning exercises, physical training, sport entertainment, strolls. Carefully and gradually should conditioning to the cold be organized, taking into account the season: sun-air baths, walking on the salt track.

Object-developing environment which surrounds children gradually supplements with didactic toys, doll's furniture, the dishes, building materials, development games. With the help of playing and fairytale therapies children emancipate emotionally, it helps to relive from irritability, to believe adults, to communicate with the peers.

Teaching of role plays develops imagination, visual and creative thinking.

Painstakingly created a “nature place” where children can observe plants and animals (fish, parrots, guinea pigs, hamsters, tortoises), can take care for them which in its turn cultivates in children careful attitude towards nature and develops the elements of ecological awareness.

Music therapy is especially required for children with intellectual development delay. Acquiring the system of musical-rhythmic habits, primary vocalization at the music classes help children unconstrainedly and without assistance perform before adults on holidays and entertainment days.

Children show surrounding social life in their visual arts, practicing with paper, clay, natural materials. At the fourth year of life children can create simple compositions and after that they organize handicrafts exhibitions.

Well organized methods of conducting classes of small groups of children according to schedule and timetable favor appearance of primary academic work: ability to understand an educational task, to follow it fulfilling educational plan, to achieve a result. Here high educational activity of children, interest and wish to study with adults should be mentioned.

Complex control of timely neurologic-and-behavioral development is realized by educators, speech therapist, teacher-psychologist that helps to plan timely a correction-pedagogical work.

Observation of neurologic-and-behavioral development was carried out one time per three months at the first and second years of life, per half-year for children at the age of 3-5 years old. The results of the observation were compared with objective rates of neurologic-and-behavioral development according to the leading levels of development (movements, regular household habits, socially-emotional habits, playing skills, speech development) which showed that overwhelming majority of children (80%) are developing uncoordinated. Children can learn movements, household habits (it can be put into II and III levels of development) successfully. Children at the age of 5 years old can acquire habits and skills of the program for junior groups of children at a kindergarten (the fourth year of education).

Mental development of children, especially speech retardation. The majority of children of all ages is found on III and IV levels of development that correspond to 2-2,5 years of life of children at the age of 5 years (first of all this phenomenon is typical for children who lived for a long time at hospitals and were sent to Center “Little Stork” at the age of 2 years). Obviously it is connected with bad heredity, long grave depression and isolation of children (for 2-3 years) as well.

However, medical and pedagogical personnel of the “Little Stork” appreciate the humanistical point of view of psychologists – L.S. Vigotskoy, I.R. Uriy, N.P. Lisina and others who allege that personally-oriented method of communication of an adult with a child and organization of leading activities can cope with the task of socialization of abandoned children.

### **Educational work at Center “Little Stork”**

Pedagogical process is carried out at the Center “Stork” by the following personnel: 5 educators, teacher-psychologist, speech therapist, speech pathologist, 2 teachers of a primary school, music teacher.

For providing a high quality pedagogical work, according to the plan, usually pedagogical meetings are held, dedicated to different questions, i.e. scheduling of an educational work on the basis of neurologic-and-behavioral development, analysis of speech development of a child, consideration of some health-improving programs of development, preparation for holidays, entertainments, analysis of open-air arrangements, improving personnel professional skills.

For complex assessment and regular observation for neurologic-and-behavioral development of every child the special documents should be processed, i.e. “observation papers” of neurologic-and-behavioral development which are completed by the educators. On the basis of the document analysis individual programs of educational-health improving activities are worked out. Psychologists work out “individual observation papers of neurologic-and-behavioral development”, on their basis a group of neurologic-and-behavioral development of every child is

determined, as well as characteristics of epicrisic (children who are going to be discharged from the hospital and transferred to a preschool center) children.

Constant observation of children development helps to make plans of individual health-improving programs. At a class which was organized at Center "Little Stork" jointly with Irkutsk regional branch of the Russian Red Cross, within the frames of the project "Help Russian children" with a financial support from the American Red Cross lessons of grammar, counting, acquaintance visual environment study are held. Music classes are aimed at development of positive emotions, rhythm and singing forming skills.

The development of a child depends on correct organization of day regimen, alternation of periods of sleep and awake, as well as the ability of the personnel to work out an educational process. Educators during regime processes pay attention to building positive, right and organized attitude of juniors to food intake, preparation for sleep, waking up, and hygienic processes.

### **Movement development**

Educators working with little children try to teach children how to manipulate objects unassisted, take in their hands a toy (for example, a rattle), overstep along a bar of a playpen or a cot, and move from one place to another. Educators who work with children at the age of 1-2 years old continue to develop and improve their movement skills. Elder children know rules and can play different group games which acquire movements ("in the forest of a bear", "sun and rain", "rod" etc).

### **Sensory development**

It is difficult to teach children because of non-generated free attention that is why educators use the method of "errands": they ask a child to perform some actions with objects, for example, to string on a stick rings of the same size, to build a pyramid, to open or close a Russian doll, to put small objects into big one and take them out of it. Educators teach elder children to name basic colors, forms and sizes of objects, show them geometric figures and teach how to recognize them, by using development games ("geometric lotto", "Figures", "gather and select" etc).

### **Learning about the environment**

With the help of educators, psychologists little children learn to recognize familiar objects, to bring them at the instance of adults, to use them according to their intended purpose, to familiarize with animals who live in a nature corner at the Center "Stork" (hamsters, fish, guinea pigs, parrots). Children learn how to look after animals, take care of them, take them in hands and not to be afraid of them. Children learn to find parts of animals' body, of themselves, of adults, to show them and name. Children learn the actions with objects with the help of development games ("Hospital", "House", "Hairdressing salon", "Shop"). With the help of table games elder children learn to name and classify objects, furniture, fruits, vegetables, pets and wild animals etc.

### **Education through work**

Younger children are taught to help an adult, when being dressed. Elder children are required to know more, concerning self-service and also children have to do some household work: to put everything in order in a game room, to make bed unassisted, to be on duty at a canteen, to do everything in order at a playlot, to help at building slides and other ice buildings made from snow. In spring children help adults to plant out plants and vegetables. Children use their habits in work with paper (ships, planes), with modeling clay, clay and fabric.

## **Children feeding**

Feeding plays the leading role in physiological processes in a child organism. Correct feeding habits impact not only normal functions of separate organs and systems but also complete immunobiological reactivity of a child, the tension of all metabolic processes, complex levels of myogenesis and cytodifferentiation acquire sufficient quality of basic food substances and their certain proportions. The fact should be taken into account that the need for proteins, fats, carbohydrates and vitamins, for water and salt varies in different age groups and also various quality of calories.

“Little Stork” all children at the first year of life are on replacement feeding. Healthy children from the first day eat milk formula. Children with weight deficit or after severe diseases, with slow physic development eat high-calorie or high-energy formula which is cooked at the infant feeding centre. Children suffering from constant regurgitation are fed with antireflux formula. From the age of 5-6 months children eat 5% or 10% cream of wheat in the capacity of additional food.

The age of a child changes the frequency of feeding changes as well. Children under the age of 3 months are fed 7-8 times a day, at the age of 6 months the number of feeding lessens to 6 times a day, of 8 months to 5 times a day.

The feeding technique is also important. Before food intake a child is changed into dry clothes. Nurses put on an apron for feeding and a kerchief, wash their hands with soap. Feeding of child is carried out not in a cot but in nurse’s arms. Thereby positive emotional conditions arise for a child, more close contact with people.

Starting from 5 months additional food is gradually used as vegetable or fruit pap: first, 2-3 grams at the end of feeding, then, daily 3 grams increasing the volume to 30 grams which a child eats for 3-4 days. Then the volume increases gradually from 10-15 grams to 130 gram of additional food. Only after that it is possible to combine other sorts of pap. Adults should keep their eye on children, whether the symptoms of allergy appeared and also control the child’s stool.

Children can drink juices from 5 months, cottage cheese from 7 months; meat pap, porridge from 8 months. Starting from 9 months children can eat cultured milk foods and eat “bit” food (under the care of adults children can eat pieces of bread, dried crusts).

From 6-7 months when a child can seat, feeding is carried out on a high child chair. During feeding a nurse should feed every child individually, sit in front of him in order to create positive emotional background for a child.

Starting from 1 year of life children sit down at the table, they should eat unassisted, after food intake they wipe their faces with facial tissue.

## **Appendix № 4**

### **List of Documents on legal control in the sphere of HIV/AIDS**

1. Convention on human rights and fundamental freedoms (Rome, November 4, 1950), with some amendments 1963, 1966, 1985, 1985. Guarantee fundamental human rights and freedoms, personal immunity, respect of private and family life etc.
2. International guidelines on encouragement and protection of human rights in connection to HIV, AIDS (Geneva, September 23-25, 1996), United Nations Office of the High Commissioner for human rights and United Nations Joint Program of HIV, AIDS. It imposes high responsibility for governments, which signed the agreement, to realize and protect de facto international norms concerning human rights on HIV/AIDS.
3. Russian Federation Constitution (which was adopted starting December 12, 1993). Guarantees fundamental citizen rights of the Russian Federation.
4. The Federal Law dated March 30, 1995 № 38-FL (with changes 1996, 1997, 2000)

- “About Prevention of Spread on the territory of the Russian Federation of a disease, called Human Immunodeficiency Virus(HIV-infection)” (further – HIV Law). It is implemented starting January 1, 2005 and is stated in the Federal Law dated August 22, 2004 № 122 –FL. The law contains guarantees that people's rights will be maintained. It also states responsibilities of the state to prevent and treat the disease, provide social support to workers who are at risk of being infected by the virus.
5. The Federal Law “About sanitary-and-epidemiologic well being of the population” starting March 30, 1999, with amendments 2001, 2002, 2003.
  6. The Criminal Code of the Russian Federation (with changes and additions) was passed by the State Duma in March 24, 1996, was approved by the Federation Council in July 5, 1996. Article № 122 “HIV-Infection” establishes criminal liability for notorious (the variant of the original) infecting of another person with HIV , and also for improper discharge of professional duties.
  7. The Family Code of the Russian Federation (with changes) was approved by the State Duma in December 8, 1995. It provides the basic state guarantee to a family, to maternity and paternity. Particularly, article № 15 determines citizens’ voluntaries of medical examination for marriage (paragraph 1), and also it is liable to divorce in that case if one of the person in marriage concealed that he suffered from sexually transmitted disease or HIV (p. 3).
  8. The Civil Code of the Russian Federation is of record on February 10, 2005. Particularly, chapter 8 guarantees honor, dignity and goodwill protection, and also compensation of moral harm.
  9. The fundamentals of the Russian Federation Legislation about health protection of citizens. Particularly, article 61 determines the list of cases when medical workers can give information (it is medical secrecy) to unknown people, articles 41 and 42 determine guarantees medically-social help for citizens.
  10. The Regulation of the Russian Government dated November 26, 2004, № 690 “About program approval of rendering free medical help for 2005. The regulation recommended to public authority of RF to approve local programs of state guarantees for citizens of RF to get free medical care”. Special medical care which is rendered at hospitals in RF, including HIV infection, is carried out for money of corresponding budgets.
  11. The Regulation of the Russian Government dated December 27, 2004, № 856 About approval of rules of free medicine supply for treatment HIV-infection in outpatient conditions at the federal specialized medical institutions.
  12. The Regulation of the Russian Government dated February 28, 1996, № 221 About approval of rules of free medical examination for inmates in order to establish HIV. In accordance with the given Regulation, examination of inmates by the clinical results should be regarded as compulsory.
  13. The Regulation of the Russian Government dated September 4, 1995, № 877 About approval of the list of evidence for HIV/AIDS examination, the given Regulation makes reference to that according to Law № 38-RF 1995 “compulsory HIV examination is forbidden”.
  14. The Regulation of the Russian Government dated October 13, 1995, № 1017 About approval of sequence of HIV examination. The Regulation provides rather strict guarantees of medical secrecy observance about HIV.
  15. The Regulation of the Russian Government dated December 1, 2004, № 715 About approval of the List of socially important diseases and the list of dangerous diseases for other people. Disease caused by HIV is included in both lists.

## Appendix № 5

### Work experience of public organizations in response to HIV/AIDS

Alongside with public specialized establishment (e.g., AIDS Center, infectious disease hospitals etc.) some private institutions provide help to HIV-infected people and their families.

Public associations (so called nongovernmental, uncommercial public organizations, foundations etc) dealing with HIV/AIDS resistance are characterized by the high level of public initiative and are of primary importance in solving social problems of HIV-positive people.

As a rule, public associations have at their disposal people who work creatively taking the initiative, they can involve in the work volunteers who work for an idea not for a fee. They are more mobile, can cover different social sectors, can involve extra, sometimes rather considerable financial and people money resources that helps to diversify the methods and increase the size of aid for HIV/AIDS-infected people.

In the early 1990s in Russia an institute of public AIDS-service organizations was established. Nowadays they exist in many parts of our country. Frequently the staff are the representatives of HIV-positive people communities, that is why, they are highly trusted by HIV-infected clients.

Every organization has its own priority of activity but the main tasks are:

- Forming and advocacy of healthy lifestyle among the population, introduction of programs concerning HIV infection prevention
- Giving social, medical, psychological and other kinds of help for people living with HIV/AIDS specially for women and children and also for difficult-to-reach groups (drug users, sex-workers, inmates)
- Social and legal protection of HIV-positive people
- Introduction in the work advanced manufacturing sciences, world innovation and domestic techniques
- Organization of mutual aid groups and support for HIV-infected people
- Development, release and distribution of printed matters containing useful information about problems of HIV/AIDS, including release of specialized newspapers, magazines, information bulletins
- Setting up and maintaining of helpline and telephone support hotline dealing with HIV/AIDS problems
- Making and support of WEB-pages dealing with HIV/AIDS problems
- Conducting of educational programs for population, expert etc

Effective cooperation of public associations alongside with specialized state institutions can considerably increase and strengthen resources of HIV/AIDS resistance.

In Irkutsk the regional branch of the Red Cross has already conducted many programs concerning HIV/AIDS.

One of the programs which is titled “Aid for the needy children of Russia”, that gives help to children, born from HIV-positive mothers and children who live at Center “Little Stork”. Also this program with organizational support of Irkutsk State Pedagogical University, the experts of the Russian Red Cross realize study group lessons about “HIV-infection and children” with students - future educators and psychologists.

Another program of the Russian Red Cross (“Care & Support for PLWHA” in Irkutsk) affords an opportunity to all people, regardless of their HIV-status, to turn to Information-Counseling Centre “Steps” of the Red Cross (35, Sverdlova Street) or they can call the HIV-hotline (200-602) where they can get reliable information about HIV-infection and ask other questions which touch upon the issues dealing with risk and prevention of HIV-infection. At Information-



Counseling Centre “Steps” one can get free and high-professional counseling by such specialists as psychologists, doctors, lawyers, one can invite a health worker to an HIV-infected child or can come to a peer support group meeting.

During 2006 the department of the Red Cross in Irkutsk implemented project called “Adults decide the children’s fate”, the first publication of this manual was prepared within the frames of the project (the project was financed by the USA Agency for International Development (USAID) within the frames of Program “Abandoned Russian Orphans” which was implemented by the American International Research and Exchange Board and by the National Foundation for the Prevention of Cruelty to Children.

Activity in this area allowed to improve the quality of the counseling services for HIV-positive pregnant women and new mothers. The seminars touching upon the issues of HIV/AIDS were conducted for 150 medical, social and pedagogical workers and teacher for the purpose of decrease in the stigmatization and discrimination rate. At the Center “Steps”, at the maternity hospitals and maternity welfare clinics “peer counselor” began their work – they are experienced HIV-positive mothers who were trained beforehand concerning counseling technique. The goal of the project is a tolerant attitude towards HIV-positive children, socially-psychological and juridical protection of families where HIV-positive children live.

### **Support and peer support groups**

Development of the support and mutual aid for HIV-positive people is important for infected people and for the society as well. Getting support, help and knowledge, HIV-infected people can improve the quality of their lives, can have influence on solving their own problems, and can make the relationships with their relatives, friends, doctors and their environment better.

Today state organizations are not able to create an all-round aid system for people infected with HIV and AIDS. Peer support groups undertake the function for providing such aid. Existence of such self-help movement helps everyone who struggles AIDS, to see the goal and find the way struggle the epidemic in the light of a concrete human life and thereby it allows creating more effective programs.

If a person faces the problem of AIDS, or if he finds out that he or someone else has diagnosis “HIV-infection” in this case he begins looking for answers to questions: how to preserve one’s health, how to avoid disclosure of status, how to establish relationships with other people. One can get answers to some of these questions from a doctor, psychologist, and a book or in the Internet.

Looking for the main answer – how to live with HIV? - people face many everyday problems: how to tell about it to a beloved person, whether to tell it or not to parents, is it worth consulting a doctor and take medicines. For most people the diagnosis “HIV-infection” – is a cause to think about things they achieved in their life and a goal they want to achieve. HIV-infected people join in groups in order to look for these and other answers.

The main condition of any group especially of the groups of HIV-infected people is confidentiality. Certainty in confidentiality of the data, which is being a person, creates confidential atmosphere among participants of the group. “What you have heard and seen about this group stays within this group” – this motto is often hung on a wall of a room where participants of peer support groups meet.

The activity basis of the groups – is a private experience of the participants. This experience allows to see that the majority of problems have many ways to be solved and that is why every participant can make the right decision which suits him best.

Every type of a group has its own peculiarities and rules. In psychotherapeutic groups (support groups) the participants under the direction of an expert try to get rid of definite psychological problems or they acquire necessary skills for them.

Mutual aid groups do not make their aim to bring participants to a certain result but they give them an opportunity to express their opinion, to share their own experience and to find an answer to a certain question. Usually mutual aid groups do not have a chief but a facilitator who watches over the observance of rules by the participants that give an opportunity to every participant to be heard.

All these groups differ in their membership, goals, tasks and accepted rules. Some of them are open to everybody and the main goal is mutual support and leisure-time organization of the participants, other groups have a constant membership whose goal is self-knowledge and personal growth; and the third group, besides mutual aid, organize a support services for HIV-infected people, preventive programs among vulnerable groups of people and population in general. The first groups are informal whose participants meet at home or at a room of a friendly organization. The others are registered as public associations and gradually become AIDS-specialized organizations.

Some mutual aid groups unite people with different opinions, views and behavior. What important is that the participants take each other for what they are without censure and prejudice. They should remember that all people at the meetings are equal irrespectively of their age, social status and other factors. Without all of these aspects nothing will come out of a confidential talk in a mixed group.

The history of peer support groups for HIV-positive people in Russia began in summer 1994, when the first meeting of a group called “Positive” was held at a flat in Moscow.

For 8 years from the beginning of Group “Positive” the HIV epidemic had spread with increased speed. The increased number of HIV transmission; age, social, geographic spread of the epidemic in Russia gradually had been leading to effective methods of problem-solving and also to high activity of HIV-positive people. During these years many informational leaflets, booklets, magazines and manuals were published, the seminars dedicated to creating and developing of peer support groups were held, great number of groups were created in Russian cities from Kaliningrad to Vladivostok.

Unlike western countries, the peer support group movement in Russia has only been arising and its potential is not being used to full extent. The biggest part of these groups is the mutual aid groups which were created by HIV-positive people. Groups for drug users exist in order to help people to get rid of drug dependence. Unfortunately in Russia the movement of peer support for teenagers, sexual workers and other vulnerable groups of people does not exist yet which can be based on learning to provide information, to support each other and to learn how to protect their rights. The groups for parents whose children are infected with HIV do not exist as well. Often the parents who try to help their children do not have knowledge about HIV.

The main result of the movement of self-help for HIV-infected people is the appearance of Russian community of HIV-positive people. Like other national and international communities, Russian community was created in order to help HIV-positive people to be heard by other people. First of all it is important to inform the society about needs of HIV-positive people, and secondly, HIV-infected people should help other people to protect themselves from the epidemic.

In Irkutsk support and peer support groups for people who live with HIV, including pregnant women and new mothers, can be found at Information-Counseling Center “Steps” of the Red Cross and at the regional AIDS Center.

## Glossary

Viral Load	the number of free viral particles which circulate in blood. Viral load analysis is based on polymerase chain reaction and it reveals the number of ribonucleic acid virus.
HIV	human immunodeficiency virus. It belongs to the group of

	lentiviruses, subgroup of retroviruses. With the laps of time it decreases the number of T-lymphocytes which is the cause of AIDS.
HIV-positive	a person who has HIV antibodies in his blood. This term is more preferable than “HIV-infected” which is found to be offensive for people’s dignity.
HIV-status	Presence or absence of HIV-infection in the person’s organism. HIV-status can be both negative and positive. If a person had a risk to be infected with HIV but HIV test was not taken it means that his HIV-status is not known.
Self-help (peer support) groups	a group of people who get together and have the same problems. Managers and responsible people in the group are the participants.
Support groups	a group of people who get together and have the same problems. the goal of the group is to share the experience, information and to provide support. The head of the group is a facilitator or an expert (i.e. psychologist )
Psychotherapy groups	one of the methods of psychotherapy. The participants of the psychotherapy groups discuss and communicate with each other in order to solve their psychological problems and the problem of personal growth. The head of the group is a psychologist or an expert in psychotherapy.
Volunteer	a person who participates in any activity and does not demand money reward.
Discordant couple	a pair of people who have sexual or romantic relationships. One of them is HIV-positive and the other is HIV-negative. The difference in HIV-status is known to both of them.
Discrimination	limitation of rights and freedoms of people because of their belonging to stigmatization group in the society. Discrimination is a direct consequence of stigma.
PLWHA	are people living with HIV/AIDS. All HIV-infected people are identified with this term. Since HIV-infection runs slowly and cannot be detected for a long period of time, that is why HIV-infected people cannot be regarded as “sick” but as a carrier of human immunodeficiency virus, that is “life with HIV”.
Palliative care	treatment and care which cannot guarantee recovery but only relieve morbid symptoms. Palliative care comprises a whole package aimed at relief of both physical and mental diseases, and also aimed at achievement of comfortable conditions of life for dying patients.
Patronage care	In the sphere of medicine is a service at state, commercial and public organizations which provides regular observation and rendering of medical services by the medical experts at home of a client.
Antiretroviral therapy	treatment carried out with special medicines which should take people having HIV-infection.
Peer education/care/consulting programs	the programs of education, care, consulting and prophylaxis , within the frames of which services are provided by a person having the same characteristics as his client (age, sex, ethnic origin, presence of HIV-infection etc).
Resistance	Getting used to the medicine –a ability of an organism, microorganism or virus to loose perceptibility towards the medicine. Resistance is one of the main problems of usage of antiretroviral medicine for HIV treatment.
AIDS	acquired immunodeficiency syndrome – a state of health which develops as a result of human immune system being depressed by

	HIV and is characterized by the presence of disease symptoms and development of secondary disease (infectious or oncological) which appear as a result of immune suppression.
AIDS-Service Organization	a medical, social or another organization or service which prevents HIV/AIDS with treatment or support of HIV-positive people.
Stigma	In the sphere of social sciences is a strong social stereotype which changes attitude towards other people, towards yourself, which is a reason for disgrace or public reprimand.
Facilitator	a person who organizes and carries out work in groups in order to raise its effectiveness. His goal is to keep up with regulations and provide good atmosphere, for group unity and successful discussion.

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## Useful information

You can get

- reliable information about HIV/AIDS
- consultation by a doctor, psychologist, lawyer
- participate in a peer support group meeting

at the Informational –consulting Center “Steps” of the Red Cross at the address:  
35-b, Sverdlova Street, Irkutsk City

HIV “hotline” telephone number: 200-602

Telephone number of managers – 200-393

Anonymity and confidentiality are guaranteed

You can get HIV testing, get a consultation with a doctor, participate in work of the peer support group at the regional AIDS Center. (90, Marshal-Konev Street, Irkutsk, City, the territory of the infectious diseases hospital). The telephone number 30-69-75