



# Story like yours





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Dear Friends!

It's a great honor for me to present you this book. It's not just a collection of stories and descriptions of some life situations. This is truly the Big Book of Hopes!

Hopes for a better life for adolescents affected by HIV/AIDS in Eastern Europe and Central Asia region, the only region in the world, where the epidemic has not stopped its growth.

There is someone's life behind each of these stories. No one can be indifferent to circumstances these children have found themselves in and to injustice they have faced. But there's something else that connects all those lives with invisible, yet strong thread – hope shared by everyone.

Hope that their life and life of their loved ones will be changed for better. Hope that they will manage to fulfill their potential and change the world for better one. Hope that we, adults, will start to understand our children better, their feelings, their aspirations, their dreams.

I take my hat off to courage of these young people. They made a leap towards peace and presented us the great Gift by sharing their life on the pages of this book. Now it's our turn: to hear, to feel, to understand and to support.

Sincerely,  
Vladimir Zhovtyak  
President ICO "East Europe  
and Central Asia Union of PLWH"

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# My name is Yana.

In fact, I'm absolutely ordinary person. Like all my peers I go to school although I don't like it very much, especially homework. In my free time I go in for sports and enjoy drawing, I like animals, I like to swim in the sea and to play football with my friends, I love my mom very much. In short, I have, like, million hobbies, so it's hard to list them all. But also I'm not like everyone else in one small aspect. Although you can't see it, I've got a virus in my body with which I live since my birth. It's HIV. And I got infected because when I was living inside my mom's stomach, we didn't get the treatment we needed in time. When I was 10, my mom told me how it all happened. To be honest, I was very frightened back then but then my mom gave me more information about the virus and I calmed down. Although it took me a long time to tell this story...

Now I know many things about HIV and AIDS, I visit meetings and trainings dedicated to these issues. And also I see how my mom trains other people, tells them about her status, that's why I also want to do this – to conduct trainings for other children like me.

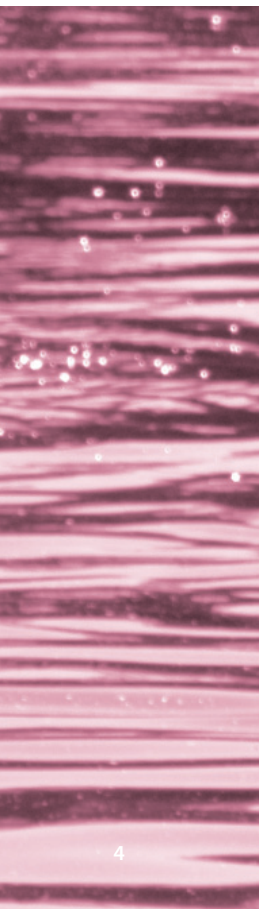
During one of such trainings I made a whole list of difficulties we face almost every day with other HIV-positive children, I'd like to describe some of them here and the ways I overcome them.

One of such difficulties is my school. I go to school every day but I can't talk to anyone about my status there. I know that I will be misunderstood and I could be discriminated against, i.e. my rights could be abused. This word I learned almost immediately after I found out that I've got HIV. Mom told me that noone should know about this disease, because people are afraid of getting infected and they may hurt my feelings. Because there are still a lot of myths about ways of HIV transmission. That's why I prefer to keep quiet at school. But it hurts me when I hear another fable about HIV or AIDS and I try to tell them the truth!!! I know cases when HIV-positive children were expelled from schools. I can't even imagine

what would I feel if something like this happened to me!!! Another difficulty is treatment. I'm taking ARV for three years now. This entire thing is very unpleasant and tiring. Of course, the worse thing is the side effects. I, for instance, have problems with my stomach quite often. Undoubtedly, it affects my active lifestyle. But I try to keep up spirits and think only about benefits these pills give my body. Also, your ARV intake should be kept in secret. When I take my pills with my friends or other people around, I tell them that those are vitamins so that they don't ask questions and can't find out about my status. Or, sometimes, I think up another diagnosis for myself. It's also very important to remember to take my medication at the same time every day. That's why I set the alarm clock in my mobile phone and try not to miss it.

All in all, I want to say that it's not that bad to live with HIV. There are much more dangerous diseases out there. Of course, when you have a foreign virus in your blood you often experience difficulties but you can overcome them all!

**Yana 14, Ukraine**



# MY NAME IS KATIA, I'M 12 YEARS OLD.

Three years ago I got a younger sister – Masha. Now she's almost 9. When my mother introduced us Masha told me that at the foster home she used to live, she was told that there was disease in her body called HIV. "I didn't eat well," confessed Masha, "and then our tutorer said that there was a worm in my stomach called HIV". "If I didn't eat everything we had for breakfast, dinner and supper, this worm would eat me inside. I'm very frightened!!!", whispered Masha to my ear on the verge of tears.

When we heard this story, we became sad and amused at the same time. Sad because the tutor told a whole thriller instead of calming down frightened Masha. And amused because the ignorance of this story, if you just think of it...

*Honestly, I'm very afraid for those children, who are told untruth and are not given information about HIV diagnosis, I take part in trainings for medical staff and teachers, where I tell that my dear little sister has this virus but it doesn't affect our life at all.*

Then we told Masha the truth about her disease. To calm her down we showed her a video about Fairytale Vitaminka – a kind magician, who helps children with HIV to take their medications correctly, to lead healthy lifestyle and don't be afraid of their diagnosis. Surely, my little sister already now has different questions about health and the way she should behave in different places. But together with my mother we're always ready to come for help and explain everything to our little Masha.

Honestly, I'm very afraid for those children, who are told untruth and are not given information about HIV diagnosis, I take part in trainings for medical staff and teachers, where I tell that my dear little sister has this virus but it doesn't affect our life at all.

I want all adults to treat children with HIV well and never hurt them!

*Katia, 12, Ukraine*

# HELLO, GUYS. I'M AYNURA.

I want to tell a bit about myself and share my feelings with you. I'm 17 years old. When I was 12 I got infected in hospital. As I found out later, I wasn't the only one who got infected in 2006. I was told about my status only two years later, when I turned 14. I felt unwell from this "news", because I didn't have idea what was going on and how I should live with it.

Now almost all fears are gone. But now another large problem is ahead of me – ARV-medicines intake, a year ago I began to take medications; I take ARV-medicines two times a day. I've got nausea after take-in. Sometimes after an hour and sometimes right after intake it starts to evert me and I vomit everything. Today I write this letter from a hospital. I'm jealous of those people, who take therapy and their stomach manages with it without problems. I've got only one wish – to learn to take pills without problems.

Even at home I have difficulties because of this. My younger sister thinks I pretend only to stay away from home chores. But I want to help her. The thing is that after treatment intake I feel weakness and I don't have strength to move. Sometimes I want to walk with my friends. After a walk I feel weakness again. My mom threatens to keep me at home. What do I do? I want to be with my friends and despite everything I keep on meeting with them. I feel myself at peace and amused in my company of friends. I enjoy spending time with them. With them, time flies and this time is full of fun.

In the end of my letter I'd like to tell you that I will reach my goal no matter what. I will take my treatment, will adhere to it and everything will be alright.

Lately, I've started to do auto-training. I hope this will help me.

*Aynura, 17, Kazakhstan*

*...I'd like to tell you that I will reach my goal no matter what. I will take my treatment, will adhere to it and everything will be alright.*

# Our world...

it would become empty and awkward if ordinary people lived in it – people with the same point of view and the same view on life.

We are all special in our own way. There are no two people alike. Something will always differ them from one another.

And I'm special too. There is no other girl with dark brown little eyes so much akin to my mom's and dark blond thin hair, which I inherited from my father. Noone lives the same life as I do and noone experienced the things that I did. Of course, I'm sure that I'm a lucky one. Because there are people, who have experienced and survived situations that were worse than mine.

I'm HIV positive young girl. I live together with my mom and my dad. My grandmother and grandfather are near me. I have the most normal, ordinary family. But everything was different earlier. I had a difficult childhood and this, perhaps, impacted my character. I was silent, reserved and calm child. I was living in my "oyster shell". I enjoyed loneliness. It was hard for me to communicate with my peers, because I knew I was different. And I often thought about this. Today you can hardly say I was like this. I don't blame my parents at all. I overcame this. I'm living, I'm glad for every day I spend near my parents, friends and relatives. And as strange as it might sound, I feel myself the happiest teen in the world. Yes, there are difficulties in my life, but I'm sure that I will overcome them.

My status... What can I say about it...I found out about it when I couldn't go to Italy. My grandma told me. I knew a lot about the disease and that noone was cured. To survive you should take pills every day at certain time. I began to take them since I turned 14. My intake of medicines consists of three pills that I take two times a day. Painlessly and calmly. This reminds me of vitamins intake for a good mood, to be honest. My medications intake doesn't disturb me at all.

Life is the most beautiful thing in the world. I'm grateful to my parents that they gave it to me. And it doesn't matter at all whether you are HIV-positive or negative person. We all are living under this blue, bright sky. Every person has the right for mistake. Because we learn from our mistakes and mistakes of our parents. I love life. And it doesn't matter that I was born the way I am.

*Gelia, Belarus*



We all are living  
under one blue,  
bright sky.  
Every person has  
the right  
for mistake.

### ***My name is Aka.***

I live in Kazakhstan. And this is my story on how I found out about HIV. Once I was invited to a meeting and there I found out that my little sister has...this disease. At that moment I felt sick and gloomy at heart. I should say that back then I didn't know almost nothing about HIV and AIDS and only knew that this is a fatal disease – they said on TV that it's "20th century plague". Like many of my schoolmates I thought that only junkies and people with bad lifestyle can be infected with HIV. And I couldn't ever imagine that such virus can get into the body of a little girl. Especially, when it is not visible to you. I was afraid for my little sister, was angry at doctors because of whom my closest person can die now.

In the public centre they told me everything about the way my sister feels now, about AIDS and HIV and how it can be transmitted and that there is treatment now, thanks to which HIV-positive people can live for long, long time. That's why I stopped being distressed about possibility to get infected as well but I was afraid that people will turn their backs at our family after finding out about my sister's status. Because these people, like I earlier, believe more in gossips and legends due to the lack of information about HIV and AIDS. For instance, many my acquaintances still believe that HIV can be contracted as flu – by simply being in one room with a positive person or by drinking from the same glass with them.

That's why friends and relatives know nothing about my sister's condition. Of course, it's very hard to keep in secret this disease but we made up another diagnosis for her, which is harmless for others and now our girl can take her pills without unwanted questions.

I think that it's very important to fight wrong attitude in society toward people living with HIV and AIDS. To do this, I believe, there should be more reliable information in schools and universities, TV and the radio. And therefore I decided that after my graduation I will definitely become a trainer and I will tell people the truth about HIV and AIDS in my country and other countries as well. And it will become my own personal contribution in fight against discrimination of HIV-positive people.

***Aka, 15 years old, Kazakhstan***

### ***My name is Kiril.***

I'm 13 now. When I was 7, I went with my mother to Kyiv to children's hospital to have my tests taken. And there I was diagnosed with HIV. I didn't quite understand back then what it meant but I noticed that my mom was very upset and became pale. I don't remember exactly but I guess my mother told me about the disease and how to live with it straight away.

The most difficult time for me was when I got to the hospital. I got pneumonia because of HIV. The hardest thing was to go through injections – needle was put into my arm and so the drop bottle was made. It hurt, but I did my best and stood strong – just kept on enduring. In this way I managed the problem of being in hospital all the time. Now I understand – although life with HIV is not simple but it's quite manageable.

***Kiril, 13, Ukraine***

**THERE SHOULD BE MORE RELIABLE INFORMATION IN SCHOOLS AND UNIVERSITIES, TV AND THE RADIO.**

**HIV-POSITIVE PEOPLE ARE AS EVERYONE ELSE, THEY ONLY HAVE WEAK IMMUNE SYSTEM.**

I was very young when I found out that my mom and brother were HIV-positive – I was only 7 years old. I knew very little about this disease back then, but I was afraid of it because my father died from AIDS. Soon I found out that there are medicines – ARV-therapy. My mom and brother will take pills and won't die. Over time I started to understand that you can't get infected with this virus if you are just living in one apartment with HIV-positive person. Therefore, when tuberculosis was compared with HIV at school, I couldn't keep silent. I told everyone that unlike HIV, TB transmits by air. And that HIV-positive people are as everyone else, they only have weak immune system.

***Seryozha, 15, Ukraine***

# Hi! My name is Kairat.

I'm 18 years old. I'm leaving school this year and enrolling to graduate school. I want to be a lawyer. But, honestly, I haven't made up my mind regarding my future profession yet, because I have many hobbies in my life. I enjoy drawing, making photos, watching interesting movies, talking with my friends.



Since childhood I've often been ill, from time to time I had to spend some time in hospital. As long as I remember my parents have always had a very tremulous attitude to me and my health. There were always tests to be taken and different doctors to be visited. Already then I understood that I wasn't like everyone else. Eventually, I've had of it – I didn't want to see any doctors, to do endless tests. And my parents persuaded me and told me that those analyses were crucial for my health. Once I asked my mom: "Mom, am I seriously ill?", "Of course you're not, why do you think like that?", answered she. An then I noticed tears in her eyes, she turned back to me and went to another room.

Then I realized that my parents conceal something terrible from me. I started to think about this often, sometimes I even didn't sleep at night. I was worried that I had some fatal disease and would die soon. And this question tortured me for many months, until I visited the training in Kyiv in 2011 to be specific. At first I didn't understand why I was invited to this training. Since the first day we were told about HIV and AIDS. And then a psychologist and my peers with positive HIV status talked to me. They told me that I also have HIV in my blood. It came out that I was infected with HIV in hospital when I was 14 while I was receiving injections. And I learned that other children (participants of that training) are like me or their close HIV-positive relatives.

*...esteemed parents, please disclose the status to your kids, speak to them as earlier as possible about this!!!*

After four days during which we had the training, I understood that I'm not the only one in the world living with HIV-infection and that this disease is not fatal, that you can live long with this diagnosis if you take pills and lead healthy lifestyle. And in the future, in several years, I might think of creating a family. Because despite my diagnosis, if I follow all doctors' instructions my children can be healthy. Today I have good immune system, but I know that sometime later I will be forced to start taking pills, when it will be necessary for my health. And because I love life I'm ready to take those pills.

I want to say to all parents of HIV-positive children – esteemed parents, please disclose the status to your kids, speak to them as earlier as possible about this!!! Noone can do this better than you. Because you know your children better.

And one more thing. There was time when I was offended at my parents because they concealed my diagnosis from me for such a long time. I met teens, who were much younger than me at the training, but they already knew their HIV-status. Then, of course, I realized that my parents love me very much and they didn't want to hurt me with their silence.

**Kairat, 18**



# My name is Dasha.

I'm 16. I have lots of good friends. I like traveling, reading books and surfing Internet. I go to school like all children. There are pros and cons in school. The major thing is much communication. I don't have parents. My close relative is my aunt I'm living with. When I was 13 she told me I had HIV. She always supports me and takes care of my health. My aunt told me that I differ from other children because there is virus in my blood. At first I got very frustrated, but then my aunt told me that there are special pills and if you take them regularly they will help you to live long life. I once read in a book: "The most important is to remember that HIV-infection diagnosis doesn't mean that life has ended. Diagnosis changes life." And I absolutely agree with the author. Complex decisions are ahead of us – who to tell and how to do it, how to accept changes in your life.

Unfortunately, we've got inappropriate attitude to HIV-positive children in our society. Parents and children, including me are interested in reaction of teachers, schoolmates and friends if they are told our secret. In such situations I feel fear and sometimes I feel even shame. But you shouldn't be sad. There is special support group that helps positive children and their families, including mine. During such groups I found out that noone should know about my disease at school. Only physicians know about it. At group gatherings social workers and psychologists tell us about health and about ways HIV-positive people overcome difficulties, they help us to overcome our fears.

At support group I understand that I'm not alone. There is a possibility to meet here other people, find new friends and the most important – to tell what troubles me to those, who will understand me.

I dream that when I grow up I will have a beautiful family. I'm anxious about my future life and who I will become in the future. All in all I want to be a social worker because I like the way girls are working at the Children center for us and I want to help people.

*Dasha, 16, Ukraine*



# MY NAME IS KARAT.

I'm 12 now.

I found out about my HIV status 10 years ago.

Then I simultaneously found out that my parents have HIV too. According my mom's words she didn't know about her status and that my father was ill for a long time.

Everything became clear accidentally.

Before my status disclosure I felt that there was something wrong with my health. I felt that my mom concealed something serious from me. Because we often went to hospital located far from us, in the city and I had my blood

taken and I took pills twice a day. Once I grew tired of taking medicines and told my mom about this. My mom started to persuade me to continue taking pills as my physician told me. Often my mum trusted me and I took them alone. I thought that mom was exaggerating

things and that I would be ok without them. I started to throw away my pills under coach. It lasted for a short time. After my mom found them under my coach, she decided to tell me everything. When I found out that ARV was the only treatment available today I started to maintain adherence to it. I hope that scientists will develop a vaccine soon and then I will become healthy again.


After I found out the truth it became easier for me and my mom to live. My mom avoided answering my questions earlier, she answered ambiguously, irritated if I insisted. Now everything has changed. We openly talk about this issue.

I have the most amazing mom in the world. I love her very much. As long as my mom is near me, I have nothing to fear. I also noticed one thing – if you think about good things and think positively you won't be ill.

When I grow up I will become a doctor and will treat other people.

*Kairat, 12, Kazakhstan*

*After I found out the truth it became easier for me and my mom to live.*



*i really want the society to understand and accept people the way they are, regardless of their status.*

## *My name is Sasha Izambaev.*

I'm 12 years old. There is a virus called HIV in the blood of my older sister Sveta. Sveta is an activist of HIV-positive people community in Russia, that's why she often appears on television, in programmes dedicated to HIV/AIDS. From time to time, my sister takes me with her. After such TV-programmes, my friends often ask me why Sveta is on TV. Sometimes I decide to say that I don't know nothing about this and sometimes I tell the truth. When they ask me at school how my sister got HIV and why they saw me together with her on TV I don't conceal anything and I tell them that my sister lives with HIV.

I'm living with my sister for 2 years now. Before that I was living with my mom. But when she died I was taken to foster family. Sveta wanted so much to take me away but they didn't allow me to do this. And they didn't allow me to come to her even for summer holidays. I was told that I can catch AIDS from her and then I'll come back and will infect with this disease all other people in my foster family. Although I knew that you can't get infected with AIDS and that HIV is transmitted in absolutely other ways I couldn't contradict. Woman who should have become a foster mom to me and several other children yelled at us so often that we simply were afraid of her and we couldn't contradict her.

And then they moved me to the foster home but I didn't stop hoping that someday, my sister will manage to take me with her. However, it came out that it was too difficult, because in Russia a person with HIV can't be a guardian even for their relative. Sveta was forced to go through many institutions and even courts and eventually she succeeded to process all necessary documents and take me away from the foster home. Then they even showed her in the news and called her "person who overcame the system". I'm very proud that my sister fought for me so hard and eventually succeeded.

When I was enrolling to the Cadet school my sister was asked whether I have HIV. To be honest, it's not clear for me why all people fear HIV-positive people so much. After all everyone knows now that this virus is not transmitted by air. I really want the society to understand and accept people the way they are, regardless of their status.

This year I visited Kyiv and I learned to conduct trainings. Later that summer I was in the summer camp and there I shared my knowledge about HIV/AIDS with other children. I believe that when you explain thoroughly about HIV-infection and ways of its transmission to people, they might change their mind and have more tolerant attitude towards HIV-positive people.

***Sasha Izambaev, 12, Russia***

# My name is Akhan.

I'm 16. I live in Kazakhstan. Our village is situated at the foothill where there is one school. The village is very small that's why everyone knows each other very well. I found out about my HIV status when I was 12. I was told that I got HIV infection at the hospital when I treated other disease.

My father disclosed me my status when he himself just found out about it. We don't have secrets in our family. No matter how hard it is we are trying to be open about everything. We have wonderful, based on trust relationship with my father. My father reads various psychological books and then retells them to me.

Three years ago one unjust situation happened to me, when the doctor in my school told everyone about my status. Other

*Thanks to my family and teenagers like me, who have HIV status, I'm living like all normal people.*

children started to avoid me and younger ones pointed fingers at me and called me names. I felt terrible. But my father supported me, I saw him standing strong in this

situation. But of course, I refused going to that school. It's hard to go to school with such pressure on your shoulders, expecting that someone might call you names again and diminish you. Today I'm taking classes at home. I feel more comfortable like this.

I'm not complaining of my health and well being. I'm feeling great. I'm going to hospital only to have another tests taken.

Thanks to my family and teenagers like me, who have HIV status, I'm living like all normal people. When I found out that I'm not the only one with this disease I grew calmer. I can talk with my HIV-positive peers without fear. We understand each other well.

I believe in everything serene the way my father taught me.

*Akhan, 16, Kazakhstan*

# My name is Victoria,

I'm 15. My mom died from AIDS, when I was 6 years old. I'm HIV-positive. I didn't know about my status when I was young. When I grew up, they disclosed it to me. I was told that in fact this disease is not that terrible if you take therapy each day. But I was afraid anyway and I'm still today! No, not to die... I'm afraid that my friends will find out about my HIV status and will turn their backs on me.

*I want to help HIV-positive children, who, perhaps, are looking for answers to their questions but don't find them.*

I have a friend, we have been friends with her for 10 years. She knows everything about me, except this secret

of mine. I think that if I tell her about this, she would stop to be friends with me, but I won't be able to live without friendship.

All problem is in fact that many people don't know the ways of HIV transmission and difference between AIDS and HIV. In this short letter I'd like to tell everyone who will read it that you should be positive in everything you do, because positive people will never get ill because they are stronger than the disease.

Now we are organizing the support group for teens, affected by HIV.

I want to help HIV-positive children, who, perhaps, are looking for answers to their questions but don't find them. I want to help such children, because you won't make any mistakes if people who already made them will help you!

*Victoriya, 15, Ukraine*



*...I was invited to the group of children like me. They became my second family.*

## *My name is Ruslan, I'm 15 years old now.*

Once on the weekend, when I was 9, together with my friend Max we decided to download a new version of the game. We didn't have computer at home back then. Without my parents' permission I took keys from the garage and rode to Max's place on my bicycle. He lived just two blocks away. But on my way I needed to cross a highway. A car hit me while I was crossing it. I lost my conscience. Everything that happened after this I found out from my mom. It came out that when that car hit me I knocked against curb. Unconscious I was admitted to intensive care where I stayed in coma for 24 hours. But I survived. I don't remember much, only that I couldn't walk properly and was staggering all the time, couldn't say clearly a word. But little by little I turned the corner. In this condition I couldn't go to school, so teachers came home to me. My friends often visited me.

Once my mother and I were invited to some institution, now I know that it's called AIDS center. My mom was very nervous, squeezed my palm all the time. We were asked to enter the room. We came in. A woman said to my mother: "Your child has HIV-infection".

Mom cried rivers of tears, me too. I understood that they talked about my health, although I didn't understand the meaning of those words... but, honestly, I was afraid. I asked then: "Mom am I going to die?"

My mom yelled at doctors. I was showed out of room. Then I noticed rushed medical staff and realized that my mom felt sick. She lost her conscience. I stood in the corridor and didn't understand anything. Now I know that they disclosed my status to my mom then. Later I understood that I got infected with HIV at hospital when I was treated there.

Now it has been three years since I started taking ARV medication. There was time when I didn't want to take them anymore. It was then that my parents and relatives told me about HIV. It was difficult for me to hear about my diagnosis. I always get support in my family.

Later I was invited to the group of children like me. They became my second family.

I found out many things during these classes – that you can live with HIV and make plans for the future if you take your medication in time and lead a healthy lifestyle. And I'm trying to do just like this and also support other children with HIV.

*Ruslan, 15, Kazakhstan*

## MY NAME IS KSYUSHA.

My name is Ksyusha. I'm 13 years old. My mother died when I was 6. I also found out something else that day. Doctors said that I had HIV. So I began to live with my granny. After some time she said that I should take vitamins to be healthy. And I still take them.

In the future I want to be a photographer. I dream of professional photo camera. I enjoy taking photos of sunny bunnies, children's smiles and their little eyes.

I also dream of visiting 7 natural wonders of the world.

I socialize with other children, who also have HIV-infection. Thanks to non-governmental and governmental organisations, we visit many interesting events that make my life informative, colorful and full. Visiting various meetings dedicated to HIV and AIDS in other countries and cities is not the only thing we do. There are interesting events in my home city as well, where we don't think of our disease at all. For instance, in spring we met participants of the Ukrainian Stars Factory and in summer we had training where we met guys from different countries. Thanks to all this, I feel that other people care for me!

I've got the best friend ever – Yana. She is not HIV-positive but she knows that I'm ill and she is ok with that. Her parents found out about my status but they didn't change their attitude towards me.

And another confirmation that life with status can be happy: I know one HIV-positive woman, who has interesting job, loving husband and recently she gave birth to a healthy boy.

With my story I wanted to show that life with status can be full and interesting, you just shouldn't give up and think positively!

*Ksyusha, 13, Ukraine*



... life with status can be full and interesting, you just shouldn't give up and think positively!

# My name is Valia.

My name is Valia. I live with my grandmother, grandfather and aunt but I call them "mum" and "dad" and I call my aunt by her name, like my sister. I also thought that I had another sister but it came out that she was my mother.

I found out about my true parents by myself, when I looked into my birth certificate. My true mother left home when I was 1 year old, then she went to prison. Now she lives separately from us but in the same building with me. She is HIV-positive but she doesn't want to take ART. I know nothing about my father and I've never seen him. I live with my grandmother and grandfather quite well but sometimes it's unbearable, because they quarrel all the time.

I'm HIV-positive person but when I was 11 I found about this by myself too. I take my therapy twice a day.

Of course, my friends and acquaintances don't know about my status, because they might not understand me and start calling me names – some of them believe that HIV can be transmitted through air. That's why when I take my pills with them around I tell them that I've got problems with my liver.

Sometimes I think that my life completely sucks but it's not true. Because there are people out there, who organize different trips and trainings for us, they care about us. Places we visit are lavish and beautiful. My acquaintances, who are also HIV-positive, have even traveled abroad and I think that sometime I will travel there with them as well.

Anyway, I've put up with everything and I live normally. The one thing that I don't like is the fact that I must have vein blood test once in three months or sometimes once in six months. So if you are HIV-positive and you're reading this – stay cool and everything will be ok!

**Valia**

if you are HIV-positive and you're reading this – stay cool and everything will be ok!



*...there are people out there, who organize different trips and trainings for us, they care about us.*

## Glossary of Terms

### Antibodies

Proteins produced by immune system to destroy infection or malignant cells.

### Antiretroviral therapy (ART)

Combination of three different medical drugs, known to be the most effective means to prevent HIV replication and reducing number of viruses to the level when they become undetectable in blood of a patient.

### EECA

Eastern Europe and Central Asia.

### Human immunodeficiency virus type 1 (HIV 1)

It is believed by scientists that this virus causes the most cases of AIDS. Infection happens when the virus injects its genetic material into the cell, stopping the cell from its normal functioning and instead making «HIV-producer» out of it.

### Human immunodeficiency virus type 2 (HIV 2)

Virus akin to HIV 1, which also causes AIDS disease. It was discovered in South Africa for the first time ever.

### HIV

Human immunodeficiency virus.

### ECUO

«Eastern Europe and Central Asia Union of PLWH».

### The UN Children's Fund (UNICEF)

The United Nations international emergency fund to help children.

### Long term Non-Progressor

A person living with HIV for at least 7-12 years and who is able to maintain healthy CD4+ count, despite the absence of antiretroviral therapy.

### Immune system

Defense mechanism of the body that recognises and destroys foreign substances.

### Infection

Microbes (bacteria, viruses, parasites) in the body. Infection can cause or not cause a disease.

### Infectious disease

A disease caused by microbe (bacteria, virus, fungi, parasites).

### CD4+ cells

Cells of immune system that play a crucial role in building attack of immune system against foreign substances. HIV causes destruction of these cells, resulting in weakening of the body's defences. There is 600-1200 CD4+ cells per cubic millimeter of blood in a healthy body. Patients with AIDS have CD4 count range under 200.

### PLWH

People living with HIV.

### Macrophage

A large immune cell that ingests infectious material and other foreign substances and stimulates the work of other immune cells. Macrophages can store large number of HIV viruses while staying alive and acting as reservoirs of virus.

### Immunity (resistance)

It is known that HIV becomes unresponsive to effective medicines (for instance, when adherence is not maintained). This happens because virus has the ability to mutate rapidly.

### Opportunistic infection

An infection that can be easily fought off in the healthy body but in the body with weakened immune system it can cause severe disease or even death.

### Adherence

Maintaining the right regimen of medicines intake.

### Retrovirus

A type of virus where viral genetic information is stored. This viral information can be copied into DNA of a healthy cell. HIV is a retrovirus; some other retroviruses cause cancer.

### AIDS

Acquired immunodeficiency syndrome.

### Acquired immunodeficiency syndrome (AIDS)

The most grievous stage of HIV-infection that happens when immune system of the body is virtually «shut down». AIDS patients often have lung-, brain-, eyesight diseases as well as other organs. It's not uncommon when they experience sudden weight loss, diarrhea and acquire some types of cancer.

### T-cell

A white blood cell responsible for immune system response to infected or foreign cells. CD4+ cells (which are one of T-cells types) become the target for HIV virus.







*All in all, I want to say that it's not that bad to live with HIV...*

*i really want the society to understand and accept people the way they are, regardless of their status.*

*... life with status can be full and interesting, you just shouldn't give up and think positively!*

*if you are HIV-positive and you're reading this - stay cool and everything will be ok!*

*I think that it's very important to fight wrong attitude in society toward people living with HIV and AIDS.*

*Now I understand - although life with HIV is not simple but it's quite manageable.*

*Thanks to my family and teenagers like me, who have HIV status, I'm living like all normal people.*

*I want to help HIV-positive children who, perhaps, are looking for answers to their questions but don't find them.*

*...I was invited to the group of children like me. They became my second family.*

*The most important is to remember that HIV-infection diagnosis doesn't mean that life has ended.*

*I will take my treatment, will adhere to it and everything will be alright.*

*And it's doesn't matter at all whether you are HIV-positive or negative person. We all are living under one blue, bright sky.*

*After I found out the truth it became easier for me and my mom to live.*

*... esteemed parents, please disclose the status to your kids, speak to them as earlier as possible about this!!!*