

# HIV, Motherhood, and Learning to Live a Positive Life

**D**uring a recent visit to Odessa, Ukraine, CommonHealth spoke with Olga\*, a 35-year-old woman who learned she was HIV-positive when she was pregnant with her son, Alexander\*. Thanks to a PMTCT program at the Kiev City AIDS Center, Alexander—now approaching his third birthday—is HIV-negative and Olga has found a network of care and support that makes staying healthy and happy much easier. Here is her story as told to AIHA staff writer Kathryn Utan.

For me, finding out that I was HIV-positive caused deep psychological trauma and feelings of confusion. I have never been a drug user and even to this day I am not certain exactly how I was infected. This trauma was further compounded by the fact that I completely lacked any real information about HIV and what having the virus actually meant, especially for a pregnant woman.

I was seven months pregnant when I found out that I was HIV-positive. I had a series of routine blood tests during a regular visit to a maternity wellness clinic and when they told me about my status, it came as a tremendous shock. In Ukraine, HIV is generally viewed as a death sentence.

When staff at the maternity clinic gave me my diagnosis, they didn't provide any information at all, not even a pamphlet or flyer about the disease. They just quickly referred me to the AIDS Center where I was tested a second time. Under such circumstances, the initial shock of diagnosis can quickly turn into utter despair. Even after receiving confirmation of the diagnosis, I was only provided with a general description of the virus, which is a tragedy

*\*All names have been changed.*

because people in this situation need more than a few rudimentary details. There is so much to learn about what a person can do to ensure he or she stays as healthy as possible, so much to learn about keeping others healthy, and so many questions that need accurate answers. The fact that I was pregnant and committed to starting a family with my husband only compounded my anxiety and sense of hopelessness.

But then some of the Center's staff explained that during the 32nd week of gestation an HIV-positive mother could take a dose of anti-retroviral medication and that she would receive two more doses during the delivery to help prevent the spread of the virus to her child. They also told me that the babies themselves receive preventive medication when they are seven days old. With this therapy and a little luck, they said my chances of having a healthy baby were pretty good. This was exactly the sort of information I had been praying for.

At first, I was terrified to tell my husband about my HIV status. In Ukraine the general attitude toward those with HIV/AIDS is exceedingly negative. People don't believe someone could have contracted the infection without bringing it upon themselves by taking drugs or otherwise engaging in some deviant activity. People don't want to talk about the disease openly and they certainly don't want to be around people who have HIV/AIDS because their lack of knowledge about the virus makes them too afraid. All of this was on my mind when I told my husband, but after the initial shock he responded with love and kindness. I am very fortunate to have someone who is so supportive and I thank God that he, like our

son, is HIV-negative. Still, he is the only person I've told. Even my family doesn't know, nor do my colleagues at work. There are too many stories about people being shunned or even abused by their neighbors and I've heard of many people who lost their jobs when others find out they are HIV-positive.

Not being able to talk to any of my friends or family about my condition is difficult, even isolating, but until the situation here changes and people know more about the virus and how it is transmitted, I feel that it's best to keep quiet. Luckily, staff at the AIDS Center gave me the names of several nearby organizations that offer counseling and support services and I started attending an NGO called "Our Family" that is affiliated with both the Center and the All-Ukrainian Network of People Living with HIV/AIDS. This group turned out to be a Godsend.

Mostly, HIV-positive pregnant women and mothers attend the meetings. Sometimes we have more than one meeting a week, but not always because everyone has children and busy schedules. These meetings are an important way to exchange useful information in an atmosphere of trust and support. If a member has questions about child care or living with the virus, she can feel secure in asking them because all the members are going through—or have already dealt with—the same things themselves. It is a very compassionate, welcoming environment in which any person can freely ask even the most personal or difficult questions without feeling judged or patronized.

The best thing about this group is that all the women who attend have become good friends. Many of us meet informally, maybe

to have coffee or to shop. We enjoy getting together with one another and we're able to communicate and share our problems without feeling neglected or ashamed. We are all in the same boat, so to speak, so the situations that friends or family who are not aware of our HIV status would not understand are easy to discuss. We all feel like we can speak about anything, share any kind of problems with this group. This is particularly important for newcomers, who are usually so depressed when they first come to the meetings. Most of them have just learned about their status and are trying to come to terms with their diagnosis. It's a very difficult time, so seeing other people—many of whom have been living with HIV/AIDS for a number of years—makes newly diagnosed women more hopeful and they soon realize that all is not lost for them.

The success of this and other support groups led the psychologist on staff at the AIDS Center to create a peer counseling program and she conducts periodic trainings to teach various counseling techniques and how to communicate more effectively with a wide range of people, especially during the difficult and stressful situations that occur after a person learns she has HIV/AIDS. I think this is really important—after all, who better to share your thoughts and feelings with than a person who is living through the same things herself?

One point that I find very interesting is the fact that the women in the family support group continue meeting with each other regardless of whether their children are infected or not because we feel safe talking with one another. We continue to share information about transmission modes, possible treatments, healthy lifestyles, and even general parenting and relationship skills.

Part of the reason we are so comfortable with each other is that we all know that a person cannot get infected through casual contact, that our healthy children cannot get infected simply by playing with infected children. The population at large, however, is not aware of all this and they are afraid to allow their children to come in contact with someone who has HIV/AIDS or even someone they suspect may be infected. Unfortunately, I think the media actually

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contribute to the stigma and discrimination that people living with HIV/AIDS in Ukraine face today. They should be a source of accurate, non-judgmental information about HIV/AIDS, but at this time they are not. In fact, for the most part, the media makes a bad situation worse. Journalists in this country fuel the fears of the public by printing sensationalized stories, half-truths, or even blatant lies rather than using their power to educate people about HIV/AIDS and how it is contracted. The sad fact is you will almost never read a positive story about an HIV-positive person in the newspaper or see one on TV.

The story of one woman from the AIDS Center is a clear example of the media's approach to its coverage of HIV/AIDS and its disregard for people who have the virus. A television reporter came to the Center looking to do a story about someone who was living with HIV/AIDS. One woman agreed to speak with them, but only on the condition that they mask her face and distort her voice so that she wouldn't be recognized by people where she worked or lived. The reporter promised that her identity would be kept secret, but when the story aired she was in full view. The reporter broke his promise and the woman's neighbors started to scream nasty things at her, telling everyone around that she had AIDS and making dirty jokes about her. They also refused to come close to her and even started to wash the elevator with chlorine bleach after she'd used it. Stories like this one make HIV-positive people even more fearful about their surroundings and about whom they can trust. It makes them more likely to turn inside themselves rather than seek out the help and support that could make their lives a lot better. As a rule, most people tell no one at all about their status or maybe just one family member. I don't know a single person who would be willing to disclose their status in public and certainly none of them would agree to make a speech on TV.

In many cases, healthcare professionals—unless they are AIDS specialists, of course—fall into the same mindset as the public when it comes to HIV. Most of the people I know avoid healthcare workers not connected with the AIDS Center because we see a marked difference in their attitudes toward us because of our HIV status. Basically, we receive all of our care from physicians and nurses at the Center. They even have a pediatrician who sees

## AIHA Voices

our children and is always ready to answer our questions. She makes herself available specifically for our group, and the same is for true for my internist.

In all of Ukraine, we have only a few professionals who really understand HIV/AIDS and know how to provide quality care. As for me and other women in the group, we prefer taking our children to the Center for any kind of care because some of us have had very bad experiences at general healthcare facilities. For example, even something as simple as getting our children vaccinations can be a problem because some physicians do not realize that vaccinations that don't use live bacteria or viruses are okay even for HIV-positive children. Other times, healthcare workers use all these extravagant and unnecessary precautions, which shows they know nothing about HIV transmission. At the AIDS Center, they know how to provide proper care without all kinds of questions and drama.

One thing I want to stress is that, for the most part, adults who have HIV were infected because of a choice they made, whether it was to take drugs or to have unprotected sex. But children who have the virus got it through no fault of their own. As a mother who is HIV-positive, I would do anything and everything in my power to protect my baby. I hope that anti-retroviral medications will soon become readily available to help these unfortunate children. And, if I had the opportunity to make the public understand something about HIV/AIDS, I would tell them that life can still be joyful even if you are living with this virus. People living with HIV/AIDS can still live long and happy lives. They can still contribute to society if that society will only let them. ■