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## A mother urges pharmaceutical companies to reduce the cost of hepatitis C treatment for her daughter

October 4, 2012, Vilnius "On behalf of thousands of mothers whose children are living with hepatitis C virus (HCV), I'm appealing to you to reduce the treatment costs for this potentially fatal disease, so that most people living on a middle-income could access these lifesaving medications", - says Svetlana Laskova from Uzbekistan in her letter to the two pharmaceutical companies, Merck and Roche. Svetlana's daughter Marina has been living with HCV for the past 10 years and has not been able to complete her treatment due to prohibitively high costs of treatment.

As the world's two sole manufacturers of Pegylated interferon (PEG-INF)—the key component of today's most effective hepatitis C treatment—Merck and Roche continue to keep the price tag for the standard 48-week course of treatment unaffordable and unacceptably high: the average cost for a 48-week course of treatment in Eastern Europe and Central Asia (EECA) is \$15,000. According to Svetlana, in Uzbekistan the price is even higher.

In order to complete her 48-week course of treatment, Marina needs another 16 ampules. Her family's income is dependent on her husband's salary. He makes \$100 a month. Marina doesn't have a job given the widespread unemployment in Uzbekistan and the fact that she's caring for her young child. In order to find the means to pay for her daughter's treatment Svetlana moved to Moscow where she currently works as a nanny for \$500 a month but that is still not enough.

"We have enough medicine to last us until February. I don't know what to do after that. Our family has no savings left, no one to borrow from anymore—and a single dose of the medication costs a bit more than my monthly salary...", - says Svetlana.

Which is why Svetlana is appealing to the pharmaceutical companies, asking them to provide the remaining 16 injections at the price she can afford to pay—at \$1,000 (as opposed to \$6,500.).

"I continue to hope that justice will prevail and that my daughter who is suffering through no fault of her own, along with millions of other young people throughout the world, will get her lifesaving treatment at an affordable price,"—says Svetlana in her letter to the pharmaceutical companies.

Exorbitantly high cost of medicines is the main obstacle to accessing treatment for hepatitis in many parts of the world, particularly in low-and middle-income countries. At this price, hepatitis C treatment remains unaffordable for both patients and their governments. At the same time the pharmaceutical companies continue to support the high prices and aren't willing to negotiate on price reduction.

In order to mobilize the community of people living with HCV, as well as their allies in Eastern Europe and Central Asia (EECA) and the rest of the world, to demand access to HCV treatment, the Eurasian Harm Reduction Network (EHRN) has launched "The hepatitis C treatment waiting list" campaign (<a href="www.harm-reduction.org/petitions/">www.harm-reduction.org/petitions/</a>) in the beginning of July, 2012. In less than 3 months the campaign has gathered more than 5450 signatures from all over the world. Svetlana's signature is one of them.

## A brief synopsis of Marina's story

Svetlana's daughter, Marina, contracted HCV 10 years ago as a result of a blood transfusion following a complicated surgery. For the next 8 years Marina had not received any treatment with the exception of Haemodez (later replaced with Normal saline (solution)) and Essentiale Forte. Just over a year ago, thanks to the donations from three different Russian charity foundations, Marina's family was able to procure 29 ampules of Pegintron. In the beginning of 2012 Marina was able to begin her treatment. Three months later her test results for HCV came back negative and the doctor decided that there was



no longer any need to continue with the treatment. However, a month and a half later, when Marina came back for her check-up, the tests showed that her viral load was higher than prior to initiating treatment.

In order to undergo the full course of treatment Marina needs 48 ampules. For now she has enough medication: there are 15 ampules remaining from her first treatment attempt; another 17 ampules were purchased using her family's savings and loans. To complete the treatment she needs 16 more ampules, which altogether cost around \$6,500. The family has depleted their savings, there is no one left to borrow from anymore and the Russian charity foundations are no longer able to help.