



CHARITABLE FOUNDATION FOR HELPING CHILDREN  
WITH BLOOD CANCER AND OTHER GRAVE DISEASES  
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To Diana Bagrationi and employees  
of the Diana Bagrationi Foundation

Dear Diana!

On behalf of the Podari Zhizn Foundation we want to thank you, your guests and everybody who participate in the concert "To Live and Remember" for the generous contribution made to our charity.

On February 27, 2017, we received 2,497 USD from your Foundation. This sum was used to help children who need to be supplied with life-saving drugs after their discharge from hospitals. In Russia, where most families cannot afford to buy expensive medications and the compulsory health insurance system does not cover some of the vitally important treatment options, charitable help often becomes the only way out for our patients.

Your donations was used to supply a seriously ill little girl, a patient of the Center for Pediatric Hematology (Moscow), with Jakavi (ruxolitinib), an innovative drug that can help improve her condition.

**Aishat Dibiralieva, 6 years old, Makhachkala (Republic of Dagestan), beta-thalassemia major**



Aishat, a small girl with ponytails, is a middle child in an unwealthy but loving family. Unfortunately, the girl is seriously ill since birth. When she was still an infant, the doctors noticed low hemoglobin levels in her blood tests. However, the anemia was not so critical until Aishat turned three. But then, after a common cold, the situation became worse, Aishat needed regular blood transfusions, then their frequency increased, and finally she was hospitalized in Makhachkala with a very severe anemia.

The girl's illness is beta thalassemia major. It is a genetic disorder affecting the synthesis of hemoglobin. Since the origin of the disease is hereditary, drugs or blood transfusions cannot lead to complete cure (the only chance of cure is a bone marrow transplant, but it is uncommon in thalassemsias). However, adequate therapy may help achieve a stable condition in such

patients, avoiding marked deteriorations.

In June 2016, Aishat was thoroughly examined at Dmitry Rogachev Center for Pediatric Hematology in Moscow. Here the most experienced hematologists gave recommendations concerning her further treatment. In particular, they decided to include a new drug in her therapy. Jakavi (ruxolitinib) was initially developed and registered as an antitumor agent, but it turned out to be helpful in many other situations. In particular, there is reliable evidence that the use of Jakavi in thalassemia may improve the patients' condition. It is especially good for reducing the spleen size (the spleen in patients like Aishat is often markedly enlarged, and sometimes it is even necessary to remove it, but this removal can cause

other complications), but it also lessens the need for blood transfusions and reduces the frequency and severity of some complications.

After the beginning of this therapy, Aishat indeed felt much better. So the treatment should be continued. Unfortunately, the Russian state public health system cannot supply Aishat with Jakavi. One of the reasons is that the use of this drug in thalassemia is off-label. Since the drug appeared at the Russian market only in the last two years, its use in many illnesses is not yet included in the treatment standards. The only chance for Aishat is charitable help. Your donation helped supply this girl with the vitally necessary drug for March 2017.

Thank you very much!

Director of the Charitable Foundation «Podari zhizn»

Ekaterina Chistyakova



Executive director of the Charitable Foundation «Podari zhizn»

Grigory Mazmanyantz