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DEBRA Russia

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[www.deti-bela.ru](http://www.deti-bela.ru)

# About the Fund



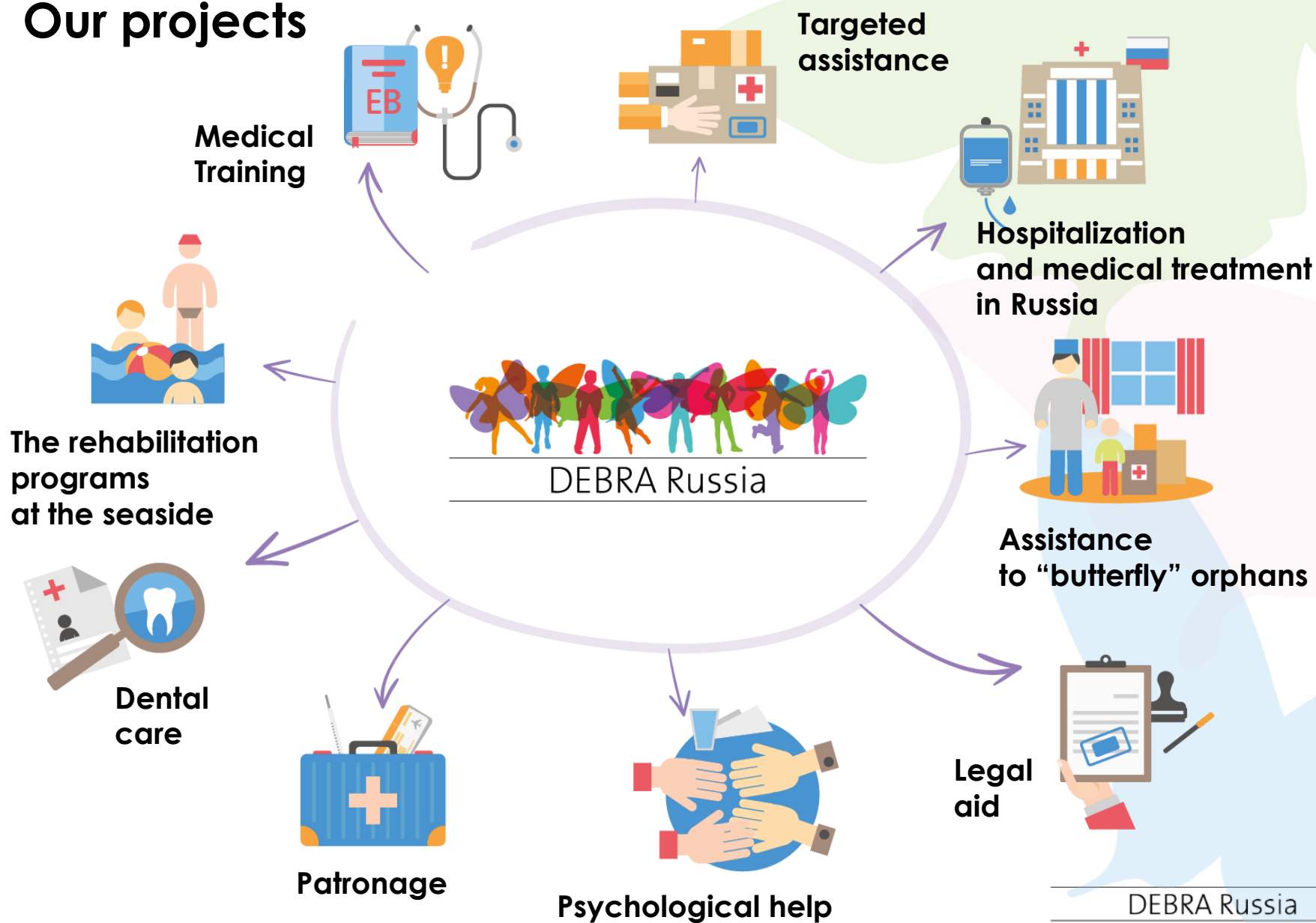
## The history of the Fund began with Anton

He was the first child who drew the attention of the media and society to Epidermolysis Bullosa. He was born from surrogate mother, his twin brother was born healthy, but Anton was sick. Anton was left in a hospital, while his brother was taken home. When 2 year-old Anton was adoptable to the USA. Anton – is a guiding star of our fund.

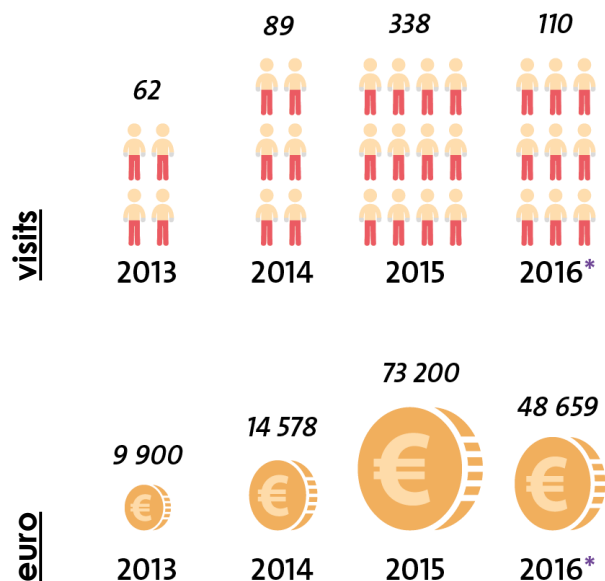
The Fund DEBRA Russia was founded in March, **2011**.  
Currently, the fund has registered about **300** children with EB.



# Our projects



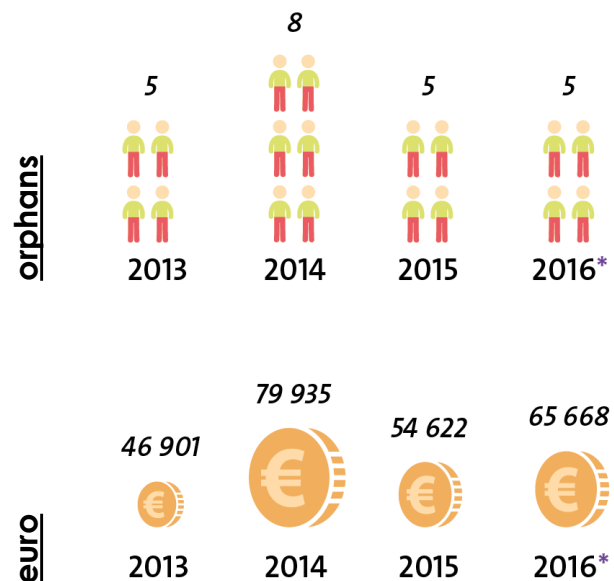
# Patronage



The Fund's medical team, which includes leading experts on EB in Russia, makes a visit to "butterflies" regularly making health control and treatment corrections if it's necessary. In case of emergency visits of specialists are made as well as to the newly discovered and newborn "butterflies" out of turn. The nurse teaches the parents how to properly care for the child and how to live with this diagnosis.

\* data for the first half year of 2016

# Assistance to “butterfly” orphans



The Fund provides maximum assistance, of both medication and bandages, for children in orphanages suffering from EB.

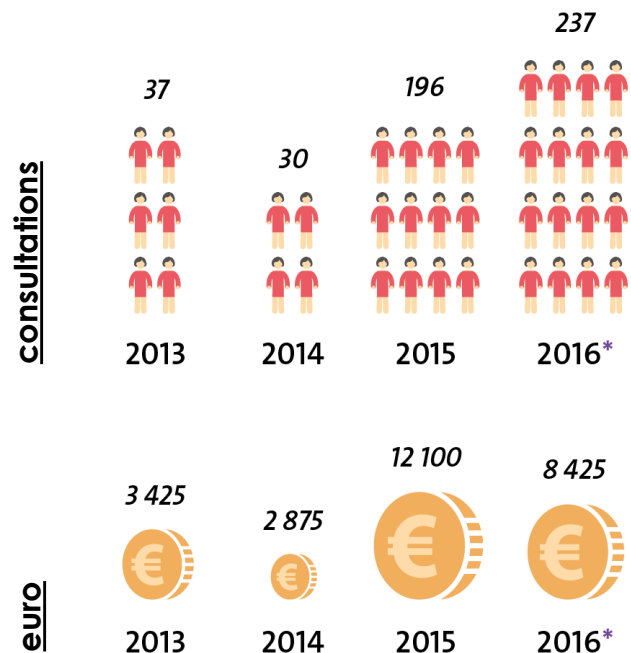
Fund provides orphans “butterflies” with everything they need: medication, bandages, hygiene and care items, as well as special diet food, clothing, shoes and household items.

Our doctors visit children, monitor their state of health and train the orphanage's staff to provide proper care for a child with EB.

\* data for the first half year of 2016



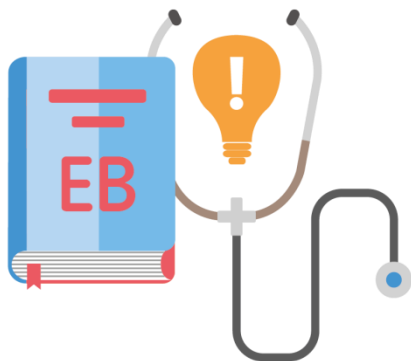
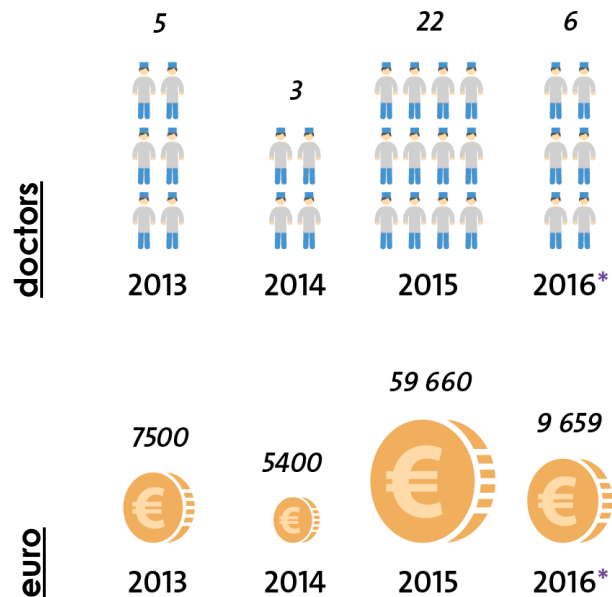
# Psychological help



The majority of families with “butterflies” live in isolation, everyday they see their loved one in pain, so they are constantly under stress and deep heavy feelings. Experienced and qualified psychologists help our children and their families going through the difficult moments, finding a solution or changing the attitude to the situation, to ease the internal emotional tension, return the confidence, build relationships with each other and people outside.

\* data for the first half year of 2016

# Medical Training



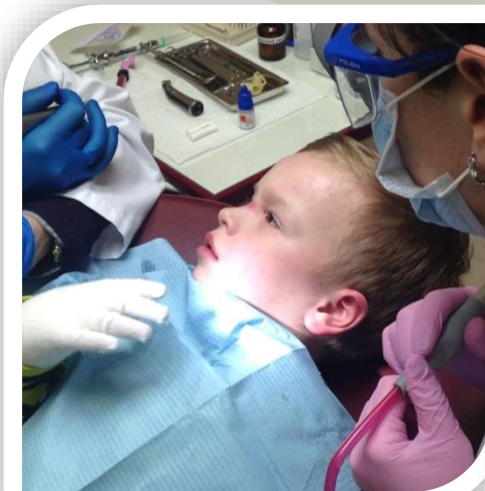
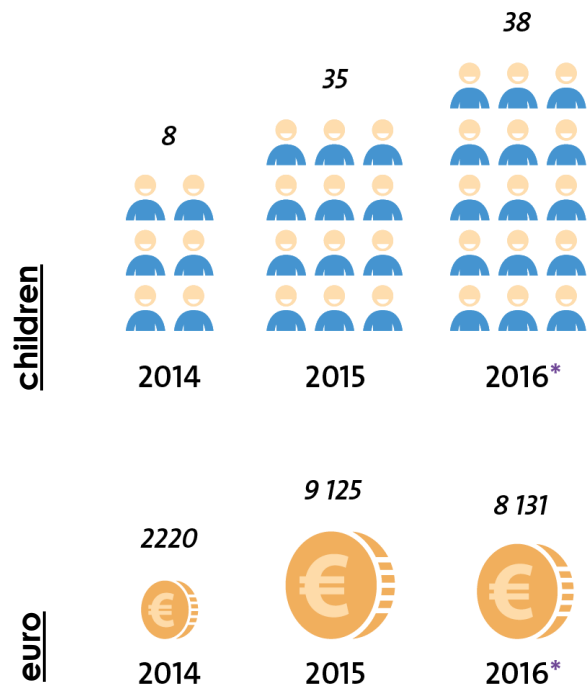
The main objective of the fund – creation of qualified medical care system to patients with EB in Russia.

At the moment the medical community in Russia has little knowledge of EB. This leads to the wrong diagnosis and wrong treatment prescriptions, which entail serious consequences.

Within this program Russian doctors undergo training in the best medical centers and clinics in Europe, specializing in the treatment of patients with EB.

\* data for the first half year of 2016

# Dental care



Oral care is extremely important for patients with EB. Dental problems affect the gastrointestinal tract. Nowadays many dentists refuse to treat patients with BE, as they do not know how to approach them.

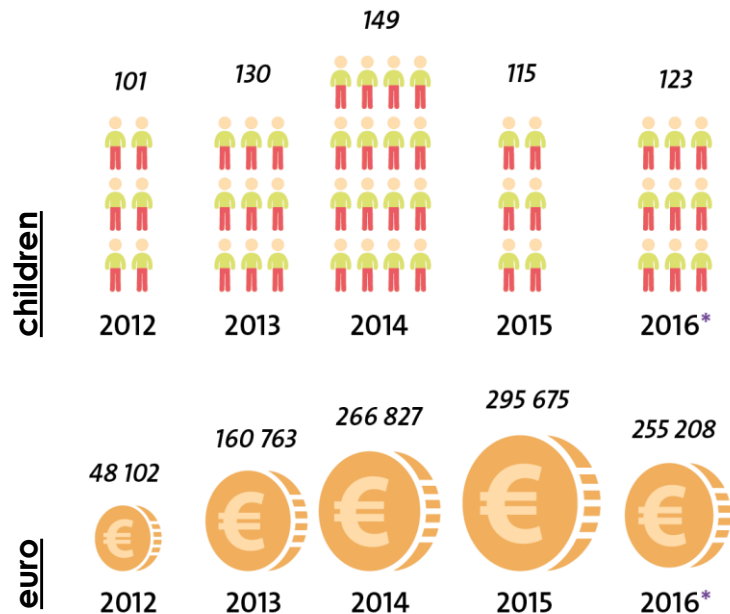
Thanks to the financial assistance of our Fund children receive dental treatment from qualified specialists. Fund is as well engaged in training of Russian dentists to properly address the dental problems of “butterflies” patients, without pain and damaging the mucous membrane.

\* data for the first half year of 2016





# Targeted assistance



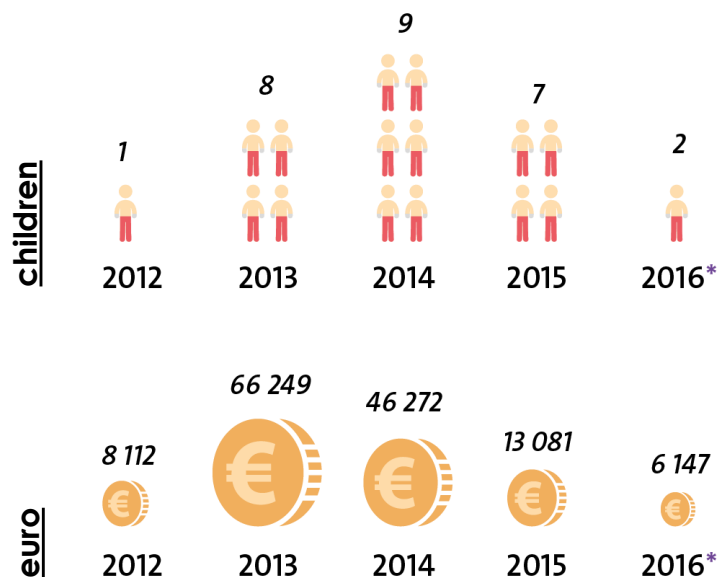
\* data for the first half year of 2016



Currently patients with EB do not receive medication assistance from the state in Russia. Therefore, the financial burden of caring for a child lies entirely on his/her parents. Almost all families with "butterflies" children are in extremely difficult economic conditions, as all the revenues are spent on the child's treatment.

We help our children – seeking sponsorship among the companies and individuals and using donations to buy medication for children. A list of medicines and bandages is determined individually for each child.

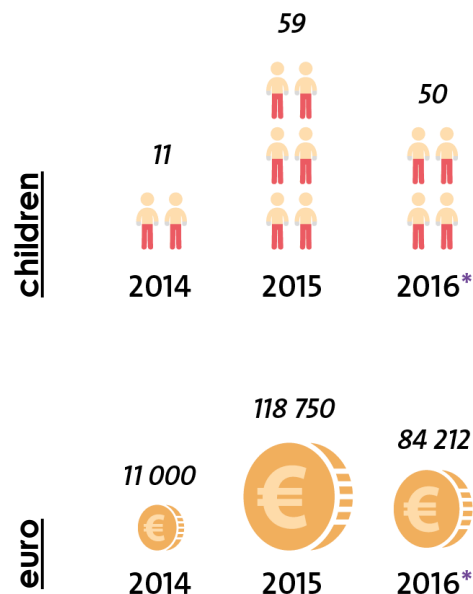
# Hospitalization and medical treatment in Europe



Before the opening of the medical center for patients with EB in Russia in 2015, the Fund sent their children for the treatments to EB House in Germany, Austria and Czech Republic. Operations and procedures that could not be done in Russia – were held there – separation of the fingers, expansion of the esophagus. At the moment the majority of procedures for EB patients are conducted in the Scientific Center of Children's Health in Moscow.

\* data for the first half year of 2016

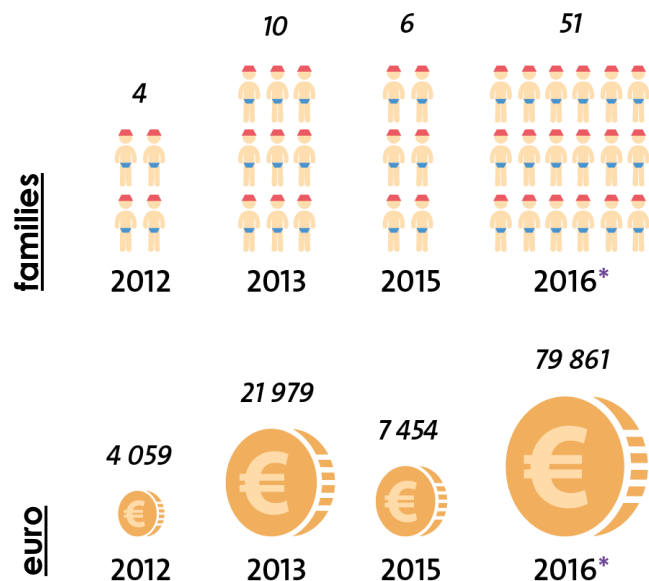
# Hospitalization and medical treatment in Russia



In January 2015 fund opened the first medical centre only for “butterfly” children within the country's leading pediatric institution based on Scientific Center of Children's Health in Moscow. The “butterflies” from all over Russia get complex medical examination and the necessary symptomatic treatment.

\* data for the first half year of 2016

# The rehabilitation programs at the seaside



The rehabilitation programs are as much important in the lives of seriously ill people as the treatment itself. Therefore, we organize a vacation at the sea for our children and their parents. Sea air and salty water are good for health for patients with EB. The time that the "butterflies" and their parents spend together is invaluable. The program allows not only to strengthen the immune system of our children, but also to improve emotional and psychological state of them and their parents.

\* data for the first half year of 2016



October 11,  
2015,

Moscow  
Russia



DEBRA Russia



Butterfly  
Children's  
Race  
is  
very  
important  
part of  
The Butterfly  
Run



DEBRA Russia

More than 60  
butterfly  
children  
across Russia  
ran  
a symbolic  
100 metres  
as part of the  
Butterfly Run





Oct. 11,  
2015,  
Moscow  
RUSSIA

1,700  
participants

1,3 million  
rubles



DEBRA Russia



2016  
7 Russian Cities  
7,000 Participants





# The Butterfly Run 2016 in Russia: Review

**7000** runners took part

**300** sponsors and partners

**199** corporate teams

**4538** Instagram posts  
using the official  
hashtag





# THE GLOBAL BUTTERFLY RUN - 2017 in participating DEBRA countries





- A single digital platform
- Global sponsors
- International awareness of Epidermolysis Bullosa
- Simultaneous runs in countries around the world



DEBRA Russia



