

## Day of Cystic Fibrosis in Russia

An annual event dedicated to the Day of Cystic Fibrosis in Russia in the framework of the European Week of Cystic Fibrosis took place at the Scientific Center of Children's Health on November 26, 2014. It has been the 8th such event at the Scientific Center of Children's Health. Children with various diseases from all the Center's clinical units attended the event, including six patients with cystic fibrosis. Such festive meetings of patients with the leading specialists in pulmonology, representatives of non-governmental organizations, public health authorities and mass media are intended to attract public attention to the issues of timely diagnosis, as well as thorough and adequate therapy of this severe hereditary disease.

Famous TV and pop stars as well as public figures participate in the event, which has become something of a good tradition. The event was supported by Armen Jigarkhanyan, Mikhail Yefremov, and Maria Golubkina (actors), Rita Mitrofanova and Olga Shelest (TV hosts), Sergey Trofimov (singer), Vadim Medvedev, Valeriya Lanskaya, and Mariya Poroshina (actors), as well as Andrey Prodeus, an immunologist and a co-host of *Zhit' Zdorovo* (Russian for *To Lead a Healthy Life*) broadcasting on Channel 1.

Metodie Bujor, a participant of *The Voice* show on Channel 1, was this year's special guest. "Participation in charity events for children suffering from such severe diseases is sacred duty of every performer, as art is not just about fame, public and show business recognition," he believes. "Many great performers that I have met, and those are Muslim Magomayev, Eldar Ryazanov, Alexander Schirwindt, would tell me that he who walks upon the stage shall bless the spectators with a particle of his heart. When performing at an event in front of so unusual, brave, and courageous kids, you must take your heart out and give it away without regrets."

State-of-the-art medicine allows for proper development of children and ensures good quality of their life if required pharmaceuticals are available and healthcare is provided in time.

But there are still problems to be solved, including lack of specialists, no outpatient care system to aid people at home, few centers and treatment rooms for adult patients, and insufficient medicinal provision.

Availability of specialized healthcare signifies a dramatic improvement of life quality and life expectancy of cystic fibrosis patients. As of now, they live for 27 years on the average in Russia, whereas in Europe, timely healthcare provision enables them to live up to the age of 50.

The objective of the Day of Cystic Fibrosis is to attract attention of public officials, healthcare workers, and Russian society to this issue. It is now imperative that all Russian patients have access to vital and essential medicines as well as therapy based on the EU standards, as this is their only chance to live a long and productive life.

*Metodie Bujor singing for little patients*

