



## **Weekly Briefing**

**Bulgaria social briefing:**

**BULGARIAN CHILDREN ARE DIEING DUE TO  
MALFUNCTION OF THE HEALTH CARE INSTITUTIONS**

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# **BULGARIAN CHILDREN ARE DIEING DUE TO MALFUNCTION OF THE HEALTH CARE INSTITUTIONS**

Recently Bulgarian society has been shaken by few cases related with children suffering from oncological diseases or other different rare diseases who couldn't receive an adequate treatment not because of another reason but due to the existing extremely bureaucratic and malfunctioning health care system and institutions in Bulgaria. The specific cases have been related to the so called Fund for Treatment of Children Centre which has been closed a few months ago and its functions have been transferred to the National Health Insurance Fund.

Everything began with a series of reports by patient organizations regarding serious problems after the transfer of the Fund for the Treatment of Children Centre to NHIF. The reports have pointed out that the parents of a child with an oncological illness have applied for medicines and treatment on April 25, 2019. For almost two months there has been no solution, and the NHIF failed to consider the statement of the Little 6 yo child Maria. The child was sick with leukemia and has been treated in hospital in Sofia. About a month ago the kid who has been suffering also from Dawn syndrome died.

Patient organizations have been warning about that case since May pointing out the delay in documentation by the NHIF Directorate, although the child has already received funding from the Fund for the Treatment of Children Centre, which has been transferred to the Health Insurance Fund. Little Maria has been born with Down Syndrome, and in 2017 she started suffering from leukemia. Doctors managed to achieve remission, but a few months ago the disease returned. In April, the girl was admitted to ISUL hospital in Sofia. A scandal broke out about her treatment since the family has been waiting the NHIF for 2 months to approve money for an emergency operation of the kid in Germany. As the Children's Fund has been closed, the money had to be disbursed by the NHIF.

The child has been infused with anti-cancer drugs, which basically are not financially covered by the NHIF and should therefore be granted as a means of treating a child. On April 25, the mother applied to the NHIF and declared that she has a donation account and if the money is collected through it, the NHIF will only have to pay for the rest of the treatment. Exhaustion continued all the time and the motives of the NHIF were that the mother has not given all the papers needed. The influx of the drugs ended and the hospital has no way but to ask for the money from the mother, so the family got an invoice for BGN 14,000. Meanwhile the kid died without the chance and opportunity to get an adequate lifesaving treatment.

This case triggered a number of protests of parents of children in a similar situation and rose up the question whether the NHIF has the capacity to work like the Fund for Treatment of Children Centre or not. So they insist that NHIF is totally malfunctioning.

They are arguing that at the time when the Children's Fund has been operated separately, drug applications were processed within one day. Now things are reduced to absurd because of the impossibility to submit applications to the Regional Health Insurance Fund, which creates a number of difficulties for families with cancer patients. Another argument is that the employees of the NHIF do not understand the nature of the issues so they cannot proceed with finding solutions of the existing cases.

A few months ago all this cases have been applied to the Fund for Treatment of Children Centre which has been designed to provide financial and organizational assistance for treatment of children abroad if sufficiently effective treatment is not available in the country. The amounts were paid individually and depended on the child's illness and the cost of treating it. The main activities of the Fund included support for medical needs of Bulgarian citizens aged under 18, who cannot be insured in Bulgaria or not financed by the National Health Insurance Fund, including: Diagnostic and therapeutic procedures; Treatment of rare diseases; Medical products; Medical supplies; Highly specialized medical devices and instruments for individual patient use; Organ transplantation and hematopoietic stem cells; Treatment in the country associated with the disease requiring corresponding transplantation. According to data from the Health Ministry for the period 2004-2018 – 9931 applications were submitted to the Fund for Treatment of Children Center. 3137 of them were for financing treatment abroad and 5965 - in Bulgaria. Most often, children are referred abroad for transplantation of stem cells, liver, kidney, hematology and oncology. In the past year, most - 38 children are targeted to Austria, Belgium, Great Britain, Germany, Israel, Italy, Luxembourg, USA, Turkey, France and Switzerland.

As it was already mentioned several times three months ago all activities currently carried out by Center Fund for Treatment of Children and the Commission for Treatment Abroad has been transferred to the National Health Insurance Fund (NHIF). This is what the parliament has decided and it was part of the government reform policy in the health care sector. The Fund has been closed down by 31 March 2019. The public council to the fund was also closed. The Commission for Treatment of Elderly People abroad is also to be closed. The main motive for this reform was due to many scandals and problems related to that Fund and its functioning. The government pointed out that sweeping reform of malfunctioning fund, which finances treatment of sick children abroad, aim to end disgrace of children dying before their applications are approved. At the same time changes have been strongly criticized by the opposition.

However, the views on the transfer of the Fund to the NHIF remain extremely separated and controversial. According to some health experts, this is a good step, as this will reduce the administrative obstacles for children to be send abroad more easily and seamlessly. However, according to another part of health experts, the decision is completely wrong because it replaces the principle on which the Fund has been established – to finance activities and medicines that the NHIF does not cover. In this situation there is currently no clarity about who will pay for medicines for rare diseases and oncology that are out of the permit list of the NHIF which pays only for drugs from the authorization list. That’s why until that time the Fund for Treatment of Children has been taken the cost of medicines that are not permitted by the NHIF.

If this issue is not regulated, mothers of sick children must urgently organize "pharmacy tourism" to buy vital medicines from neighboring countries. According to the patient organizations, about 200 children in Bulgaria suffer from cancer and rare diseases annually, so the scale of the problem is serious. At its last meeting, the Fund's Public Council found it had problems with buying medicines for 38 children. Patients' organizations therefore suggested that such medicines could also be delivered to pharmacies outside the hospital. Currently only hospitals can buy unregistered medicines.

However the way of functioning of the Fund for Treatment of Children Centre during the time of its existence has been also problematic and highly controversial. Through the years there have been a number of scandals related to the Fund and its government. Some of its ex heads have been even accused and prosecuted for financial defalcations.

A clear evidence for the malfunctioning of the Fund for Treatment of Children Centre as well as the NHIF system is the second case that has been announced largely in the Bulgarian media that coincided with the case of the Little Maria.

The parents of a 5-year-old child from Rousse, who died of leukemia after the Fund has refused funding for treatment abroad, condemned the Ministry of Health (MH) and the National Health Insurance Fund (NHIF) for a second time for a total amount of BGN 100,000. The decision of the administrative court in Plovdiv was the second after the Supreme Administrative Court (SAC) annulled the first one because of irregularities in the claim and in 2016 and returned the case for reopening in Plovdiv from another chamber of the same court. The case, which the parents of the young Gabriela Yordanova started against the Ministry of Health and the NHIF – as a successor of the Fund for the Treatment of Children, which partially succeeds the Transplantation Fund Center under the State Responsibility Act and under the Protection against Discrimination Act. Little Gabriela died on September 3, 2012 in Italy after a bone marrow transplant operation. The children succeed to receive treatment abroad, but thanks to

the donations of hundreds of Bulgarians. However, due to the clerical refusal to fund, the girl went for the operation too late and the doctors there fail to save her.

The motives for the refusal of the state funding were that Gabriela has a bigger sister and that the two children have full compatibility so that transplant can be done in Bulgaria as well. At the same time, however, the Fund gave money to two other sick children for treatment abroad, although their cases were similar. After the child's death, parents also file a case of discrimination, which they earn.

Unfortunately these two cases are not isolated but they show some very serious and deep problem related to the malfunctioning of the Bulgarian health care system as well as the ridiculous bureaucracy due to which children die not because of lack of opportunities to be saved but due to non-functioning system and institutions. Parents who has misfortune to face with such terrible hardship for their children to suffer from a severe and rare disease are forced into desperation to seek salvation by organizing donation campaigns rather than relying on the existing child treatment funds that should be guaranteed by the state. This is directly corresponding to the slogan of a recently born social networked movement called “The System Kills Us” which started as a community of mothers of children with disabilities. After being put at a disadvantage for years, they managed to mobilize and organize eight protests in last three years, which became popularly known as “the protests of the mothers”.

Extremely disturbing and worrying information that has been announced as well is that even if the children suffering oncological or rare diseases have a chance to be approved for financing of their treatment abroad Bulgarian children finally again are being refused receiving treatment because of the existing distrust in the National Health Insurance Fund (NHIF) by many foreign hospitals. Many healthcare facilities outside the country have refused to treat Bulgarians because of fears that they will not receive the due funds in time from the NHIF. Recent cases of such refusal are the following:

a 5-year-old child with heart problems who applied for treatment at Cologne University Hospital, where he was refused and another case for a 9-year-old boy named Stefan, who was also not approved for treatment in Romania. The reasons for the refusal are clear - distrust in the NHIF due to too many overdue payables of the fund.

Patient organizations in Bulgaria have warned of such cases in about 2-3 months, when it became clear that the Fund for Treatment of Children Abroad will be closed and will pass under the National Health Insurance Fund. According to the patient’s organizations, the foreign hospitals preferred to treat the Bulgarians through the Fund, but after that the decision of the government, stipulated in the State budget for 2019, the situation changed - the healthcare establishments abroad have no trust in the NHIF.

The National Health Insurance Fund (NHIF) has sent to the Minister of Health proposals for urgent changes in the legislation. The proposals aim to ease the procedure for submitting applications. An explicit text is provided for an alternative possibility for the applicant, with the consent of his / her legal representative, to authorize the treatment hospital to submit to the NHIF an application on his / her behalf by completing the required documentation. This will shorten the time for processing applications. At the same time there should be measures for improvement of the payment sustainability for the foreign hospitals and other institutions in order to improve the NHIF credit of trust.

Whether these measures will be applied immediately and there will be significant improvement of the way the system works is about to be understood. One is clear that something has to be done in order to stop this wicked practice causing death to the children of Bulgaria and expanding and strengthening the newly emerged networked social movement called “The System Kills Us”.