KOMF`s POSITION
ON THE TREATMENT OF CHILDREN AFFECTED BY LEUKEMIA

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KOMF:

16 non-governmental organizations working in the area of child protection in Kosovo have joined with the purpose of further coordination of their efforts in child protection, having a mission to protect, respect and advance the wellbeing and the rights of children in Kosovo.

Member organizations are: Associazione Amici dei Bambini, Association for Social Training, Research and Advocacy - ASTRA, Initiative 6, Center for Protection of Victims and Prevention of Trafficking in Human Beings PVPT, One to One Children’s Fund, One To One Kosova – Center for Counselling of Families, Youth Organizations Akti, Save the Children, Hope and Homes for Children Kosovo, Terre des hommes, World Vision, SOS Children’s Villages in Kosovo, OPFAKKOS, Kosovo Education Center - KEC, Civil Rights Program and VoRAE.
Child right to healthcare

Child right to healthcare is guaranteed both with the International Convention on the Rights of the Child - CRC, as well as domestic legislation. CRC gives children the right to enjoy a better health and benefit from services for the treatment of illness and rehabilitation of health\(^1\). The right to protection and care necessary for children is guaranteed by the Constitution of Kosovo\(^2\). This right is additionally guaranteed by the Law on Health\(^3\).

The Law on Health envisages the provision of all-inclusive and non-discriminatory healthcare services in a healthcare standard equal for all citizens, thus providing for required standards for levels of healthcare. However, in the absence of a law on transplants, advanced interventions are not allowed, ensuring treatment for many children\(^4\), who are in need for marrow transplantation, a known transplantation for children suffering with leukemia.

Healthcare services, are guaranteed under Article 27 of the Law on Health of the Republic of Kosovo, including:

a) Primary services\(^5\),

b) Secondary services\(^6\), and

c) Tertiary services\(^7\).

Tertiary examinations are done in the Pediatric Oncology Clinic, but not when there is a need to provide more complex interventions, due to the lack of a legal basis.

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\(^1\) Article 24, Paragraph 1 of CRC  
\(^2\) Article 50, Paragraph 1, Constitution of the Republic of Kosovo  
\(^3\) Law on Health No. 04/L-125 envisages the provision of inclusiveness and non-discrimination: equal healthcare for all citizens and residents by ensuring the standards during fulfilling the needs at all levels of healthcare as well as ensuring healthcare without discrimination on basis of: gender, nation, race, color, language, religion, political preferences, social status, sexual orientation, the level of physical or mental abilities, family status, or age.  
\(^4\) Directorate of the Pediatric Clinic in the Kosovo Center of University Clinics – KCUC  
\(^5\) Article 18, Law No. 04./L.-125 on Health  
\(^6\) Article 19, Law No. 04./L.-125 on Health  
\(^7\) Article 21, Law No. 04./L.-125 on Health
Clinical treatment of cases with leukemia

Leukemia is a serious disease that unfortunately does not spare children and requires very costly treatment. As such, unfortunately, this disease is emerging as a challenge to Kosovo society, having into account the number of children affected by Leukemia, in Kosovo.

From January to October 2014, 36 children were diagnosed to be affected by malignant diseases, of which 17 with leukemia. The Ministry of Health has ensured treatment abroad for 13 children in 2014, who are being provided treatment. The Ministry of Health has recently received two additional requests from cases with leukemia, and 21 cases are being treated within Kosovo. Of all these cases, only one failed to be treated abroad and resulted with fatality8.

Meanwhile, the biggest issues directly affecting treatment of children with leukemia are related with early diagnosis, which do not occur as a result of delays and inadequate management of cases in the primary and secondary level, but also due to the lack of diagnostic equipment, and extensive non-functioning of diagnostic equipment donated to the hospital for leukemia, failure to provide room in KCUC for diagnostic equipment and dilemmas on laboratory equipment and the current lack of funds for treatment abroad. The Pediatric Oncology Clinic at the KCUC still doesn’t have a parameter to measure the extent of the treatment of leukemia and other cancerous diseases in children. As a result, this clinic does not enjoy sufficient trust of parents to treat children with leukemia domestically, making a significant number of people seeking treatment abroad. This is also confirmed by the fact that doctors are under a significant pressure to provide families certifications for treatment abroad.

Managing the budget for leukemia

The total budget for the health sector in Kosovo for 2014 was €114 million. Compared to the budget of 2013, this year’s budget was increased by €7 million.

The Ministry of Health has allocated for the public pharmaceutical sector, in 2014, € 22.5 million, and €18 million for the Hospital and University Clinical Service of Kosovo (HUCSK), which also includes KCUC for drugs and expendables. Additionally, over €4 million were dedicated for primary health care9.

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8 Data from the Information Office of the Ministry of Health
9 Information Office of the Ministry of Health
Financing of HUCSK (as new body established based on the new Law of Health) is realized by the Kosovo budget and implemented according to the Law on Public Financial Management and Accountability\(^{10}\).

The budget for treatment outside public health institutions for 2014 was €3 million. Meanwhile, in 2013, 1400 cancer patients applied for treatment with the funds of this budget\(^{11}\). Of these, only 60 percent were sent abroad for treatment.

Every patient who has benefited from the fund for treatment outside public health institutions is supported with a maximum of €30 thousand, as provided with internal regulations of the Ministry of Health\(^{12}\). In March 2014, the Prime Minister dedicated a fund of €5.5 million for the treatment of leukemia.

This fund of €5.5 million was not allocated in full to the MH\(^{13}\). However, the majority of cases which needed treatment abroad were delivered from this fund.

According to sources of the Health Directorate of MH, a current problem is the lack of specific agreements with hospitals abroad, through which exact prices for treatment of cancerous diseases in children is stipulated.

In addition, families continue to follow old procedures, envisaged under the Administrative Instruction for treatment outside public institutions, which provide for a maximum amount of €30 thousand for any disease. The fund of €5.5 million guarantees full treatment of patients.

\(^{10}\) Law No. 04/L-125 on Health, Article 65

\(^{11}\) Director of the Health Department in MoH

\(^{12}\) Data from the Health Department in MoH

\(^{13}\) Directorate of the Health Department in MoH
CONCLUSIONS:

• There are problems with diagnosing children affected by leukemia, as the hospital has never managed to perform all required diagnostic examinations for children who are diagnosed or who should have been diagnosed with leukemia. At the same time, there is a lack of adequate investments in diagnostic equipment for leukemia in children, as indicated by the fact that leukemia analyses are done abroad, as they cannot be conducted in our hospitals.

• There is a lack of comparative data or statistics related to leukemia in children in Kosovo. As a result, it is not known if this serious disease has increased or declined in the recent years. Hospitals only possess quantitative data for 2014, in relation to with cancer diseases in children, thus providing only recent cases affected with leukemia, from January 2014 until September 2014 (36 children diagnosed with cancer, including leukemia). Moreover there is a lack of a specific comparative registry for cancer, which would be used to keep historical patient data, accurate diagnosis, methods of treatment, etc. MoH should keep such a register, in addition to all qualitative and quantitative data which show the trend of the disease. MoH and other healthcare institutions should also have prevention plans for cancer, and specifically for leukemia.

• Hospitals lack specialized human resources for the treatment of leukemia, despite the fact that continuous professional capacity buildings at all levels of healthcare is envisaged by the Law on Health. The Pediatric Oncology Clinic only includes pediatricians who have medical experience in KCUC, where they also received their oncology specialist title, through a decision of the Minister of Health, but there are no subspecialized pediatric Oncologists.

• There is an insufficient budget to ensure medicines, and as a result of this problem we have faced a number cases which, in an unorganized manner, requested funds for treatment abroad. The decentralization of the budget remains an issue for the Hospital and University Clinic Service Kosovo. There are uncertainties regarding reimbursements for medicines by the Ministry of Health, as MoH has never managed to reimburse medicines to patients suffering from leukemia. A solution for this is the possibility to increase the current budget for medicines and providing oncology medicines under the responsibility of clinics.

• There are further gaps in the legal infrastructure as the right of children to healthcare services and services free of charge will be denied, until there is full regulation of such laws, which are essential and necessary. Non-implementation of the Law on Health Insurance and the lack of law on transplantation of organs continues to be an issue further increasing this gap.

14 Directorate of the Health Department in MoH
15 Article 27, item 4, Law on Health
16 Data from the Hospital and University Clinic Service in Kosovo
• There is a lack of parameters to measure the extent in which the disease can be treated in Kosovo, an issue that not only causes confusion among staff working with leukemia cases, but also results with work not in the child’s best interest.

• There is a lack of trust of parents in health institutions as a result of problems in communication with medical staff. Inter-institutional communication is poor, which has led to delays in the provision of treatments abroad. For example, there were been cases where KCUC doctors have not provided sufficient information on the patient or the information was not sent in time to the officials of the Ministry of Health. Consequently, there were delays in the treatment of patients.

• There is no sustainable fund for treatment of children with leukemia abroad, whereas the fund of € 5.5 million is seen as a solution until to the establishment of the Health Insurance Fund for leukemia patients in need of treatment abroad. This fund should be provided on this level, until the implementation of the Health Insurance Law starts.

• There is a lack of specific agreements between international hospitals and MoH, which has resulted in high costs of MoH in many hospitals, selecting them without competition.

• There is a lack of blood for transfusion to children with leukemia, also for the fact that the National Center for Blood Transfusion consistently lacks blood and has insufficient volunteer donors. For this reason, we consider that it is necessary to develop concrete incentives for voluntary blood donors.

• There is a lack of staff of psychologists and social workers in hospitals, who should work with children affected by cancer diseases, such as leukemia, and their families.
RECOMMENDATIONS:

Coalition of NGOs for Child Protection, with the aim of ensuring better medical treatment for children suffering from leukemia, recommends the following:

- To urgently functionalize the diagnostic equipment for leukemia. Given that KCUC possesses expensive diagnostic equipment, maintenance solutions should be urgently found to ensure their functioning. By end of 2015 to secure additional equipment and reagents necessary for them to perform essential analysis to diagnose leukemia, and monitor the disease.

- To maintain records and develop a database, storing all accurate data on leukemia, given that there is a lack of accurate data both health institutions as well as the Ministry of Health. In parallel to the Health Insurance Fund, work should be done towards the establishment of a Health Information System, to ensure a database with accurate data for all diseases. By 2015, to develop prevention plans, based on accurate statistics on the number of people affected by leukemia.

- To work in adding specialized staff for the treatment of leukemia. In this situation, the Ministry of Health, in the medium term, should ensure specializations in the field of Pediatric Oncology and in the medium term it must provide training for staff members in working in children’s oncology.

- To increase the budget for oncology medicines because, according to experts and medical professional, it is insufficient and there is an urgent need to increase the budget for cytostatic medicine. At least by 2015, to reinstate the funds planned in 2013. The budget for medicines for 2015 should be at least twice the amount for 2014. The budget for Hospital and University Clinical Service in Kosovo should also be decentralized\(^\text{17}\).

- To immediately begin with the implementation of the Law on Health Insurances and to urgently initiate the drafting of the law on transplantations. These two sets of laws should begin to be implemented at least by mid next year, and there should be no more delays of deadlines for the establishment of the health insurance fund.

- To define the parameters of the level of leukemia treatment in Kosovo, considering that there is a significant pressure by family members on doctors to send their children abroad. Hospitals should urgently define a clear picture of the level of parameters for the treatment of leukemia in Kosovo in order not to allow treatment abroad where not necessary.

- To work towards a better communication between doctors and family members with the aim of restoring the trust of families over local health institutions. HUCSK Management should urgently take measures to regulate the communication between staff and patients in order to eliminate communication barriers imposed by the Pediatric Oncology Clinic. To work in a 3-year plan with the mid-level staff and specialists for a better communication with parents.

- To establish a sustainable fund for treatment abroad of children suffering from leukemia, until the Health Insurance Fund is applied. To work towards a better management of the fund for treatment abroad, producing budget analysis and strategic plans, in the absence of data and also due to the increased ad-hoc budget. Ensure analyses are made based on the data that already available in MoH and make strategic planning for the period until the start of health insurances. If necessary, this part should be regulated by law.

\(^{17}\) Data from the Hospital and University Clinic Service in Kosovo
• To sign specific agreements between international hospitals and MoH, to ensure, through an international tendering procedure, contracts with hospitals abroad for treatment of leukemia.

• To implement direct investments in public awareness on voluntary blood donation so that the National Center for Blood Transfusion has no shortage of certain blood groups. MoH must double the budget for awareness campaigns for blood donation for 2015.

• To urgently employ psychologists for treatment of children, considering that patients during and after oncological treatment suffer severe trauma, and publish, as soon as possible, announcements for psychologists to work with children and their families.

Given the guaranteed right of children to access to quality health services and the fact that children’s health today guarantees a prosperous society for Kosovo tomorrow, KOMF expects that the recommendations will be taken into consideration by public institutions mandated to ensure the health of children.
KOMF has a new website now! Find out the latest information on child protection in Kosovo at our official site: www.komfkosova.org

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Advance protection of abandoned children
Children are not a priority for the politicians
Media alongside children

• Explain the delay of payments of the social schemes!
• Think about the children in need!
• Child abuse in the media, legal and ethical violation
• Together for Children
• Protest against discrimination
• We want to know our rights!
• Is the best interest of the abandoned children being respected in Kosovo?

Letter to the Government of Kosovo
Letter to the Prime Minister
Workshop with the Media in Kosovo
Agreement signed between KOMF and the Press Council
Down syndrome Kosova
KOMF marks the International Day of Convention for Child Rights. Children ask for more information
Analysis on the protection of abandoned children in Kosovo (0-3 years)

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