



Weekly Briefing

North Macedonia social briefing:

The Cystic Fibrosis Association protests against the Government urging for the procurement of a life-saving medicine

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The Cystic Fibrosis Association protests against the Government urging for the procurement of a life-saving medicine

Summary

In the course of only 2 months, the Cystic Fibrosis Association of Macedonia has organized several protests. They have aimed to put pressure on the Government to procure a medicine that can help manage the symptoms of cystic fibrosis (CF). The protests have also served to put the spot-light on the institutional negligence demonstrated by the authorities towards patients suffering from CF and other types of rare diseases. Many of the nearly 150 CF patients in Macedonia choose to leave the country and seek treatment in countries with better healthcare systems. Others are left fighting the healthcare system in addition to their daily struggle for air and survival.

Nearly 150 patients suffer from cystic fibrosis (CF) in Macedonia. CF is a genetic disorder that affects the respiratory, digestive, and reproductive systems. It is caused by a gene mutation, which can cause chronic lung infections, difficulty breathing, and malnutrition. The severity of the symptoms can vary widely, depending on the type of mutation a person has and other factors. The only salvation for patients with CF is either a lung transplant or modular therapy. Trikafta (also known as Trifakta) is a type of modular therapy that has been shown to be a highly effective medication in treating patients with CF. Overall, the track record of Trikafta in treating patients with CF has been very positive. It has been shown to be a game-changing therapy for many people with CF, dramatically improving their quality of life and extending their life expectancy. It is estimated that providing the therapy for a hundred patients in Macedonia would cost about 15 million euros annually. But each country procures this drug at a different price and under a different contract. The prices are also much lower in countries that procure therapy for more patients, such as Croatia and Serbia. Although the medicine is provided by the public healthcare systems of Montenegro, Serbia and Croatia, it has not yet been made available for CF patients in Macedonia. Pushing the Government to procure this life-saving treatment has been one of the priorities of the Cystic Fibrosis Association - Macedonia. And it has been one of their demands at a protest organized at the end of December 2022.

On the 26th of December 2022 the Cystic Fibrosis Association organized a protest in front of the Ministry of Health. As they said, despite the promises they had received from the Ministry, there is no improvement in the treatment of the disease, and the health condition of CF patients is deteriorating. The Association has led an active campaign to encourage the relevant institutions to introduce modulatory therapy for all patients. Over 10,000 signatures had been collected in support of the December petition, which urged the Government to procure the therapy. "This therapy fundamentally changes the condition of the patients. But we have not received an answer as to why the therapy has not yet been provided and whether it will be provided," said the Association. In addition to the request for modulatory therapy for all patients with cystic fibrosis, the Association has pointed to the necessity of the Clinic for Pulmonology and the Clinic for Children's Diseases to create conditions for the treatment of patients according to the protocols for the treatment of this condition by forming expert teams and appropriate and standardized hospitalization conditions.¹ The first protest was ignored by the authorities, who took no action to respond to demands of the Association. Outraged by the ignored attitude of the authorities, the Association announced a second protest for the 4th of February. We do not ask for anything more than what is due to us as health care, the representatives of the Cystic Fibrosis Association said. "When there is a cure, there is a life", "Life cannot be calculated", "Your late decisions cost life" - were some of the slogans displayed on banners at the protest, which was held in front of the Government, where a hundred citizens came out as a sign of support for cystic fibrosis sufferers.

In response to the protests the authorities have said that the procedure to obtain the modern medicine "Trikafta" is complicated. They also added that they have made calculations and analyzes for how many patients the cystic fibrosis drug "Trikafta" should be procured and where to find money, since the budgets of the Clinics do not provide for this purpose. Prime Minister Dimitar Kovacevski has clarified that they are looking for ways to buy the drug. "We don't want the institutions to see us as just a number that protests against them or has something personal against them. We are in a situation where we just want to save our loved ones! There will be another protest if the minister does not stick to his word that things will move

¹ Patients with cystic fibrosis will demand the right to medicine in protest, published on 25.12.2022, available at <https://tocka.com.mk/vesti/432006/pacientite-so-cisticna-fibroza-na-protest-ke-go-baraat-pravoto-na-lek> accessed on 12.02.2023

dynamically and by the end of the year there will be medicines for 30 patients, and for the remaining they will be delivered in the year," the President of the Association said following the protest.²

The Ministry of Health informed that for the procurement to be realized - three laws must be changed. This means that the Government should prepare the amendments and submit them to the Parliament, where the MPs will have to express their opinion through voting. These moves however have come too little too late. One CF patient passed away several days after the second protest was held: "We tried to provide the drug "trikafta" for the most critical patients, among whom was Blagojce, and that process lasted some two and a half years, we held discussions with the competent institutions, but, unfortunately, when we realized that it might be too late and that the problem did not exist to be resolved with talks in the institutions, with meetings and pleas, we decided on protests and greater pressures, but, unfortunately, Blagojce could not stand it and died", explained the president of the Cystic Fibrosis Association. He further added that "Many of the patients are in other states, which are covered by healthcare. After some disappointment with the whole situation, we wonder if it would be better for us to move out as well. But our goal is to bring the medicine to us so that our citizens, patients and their families can stay here, not look for a solution in another country."³

Despite the Cystic Fibrosis Association's active campaign and protests, the necessary therapy has not yet been made available for CF patients in Macedonia. The authorities have said that the procedure to obtain the medicine " is complicated, and they are looking for ways to buy the drug. Nevertheless, due to the delayed response of the authorities, a CF patient passed away several days after the second protest was held. This situation highlights the urgent need for authorities to respond to the demands of the Cystic Fibrosis Association to ensure that patients receive the treatment they require. The absence of cystic fibrosis treatment in Macedonia is just one example of the deteriorating state of public health in the country. The

² The question is whether it is better for us to move out to find a "trikafta", published on 11.02.2023, available at

<https://acf.mk/zadovolni-sme-od-rabotnata-grupa/> accessed on 05.03.2023

³ The question is whether it is better for us to move out to find a "trikafta", published on 12.02.2023, available at

<https://acf.mk/prasanje-dali-e-podobro-i-nie-da-se-iselime-za-trikafta/> accessed on 05.03.2023

difficulties that CF patients are facing, from delayed treatment to the need for costly therapy, are indicative of the broader issues within the Macedonian healthcare system. The country's healthcare system has been significantly impacted by neoliberal policies, with inadequate funding leading to a lack of resources and medical equipment, limited access to medicines, and long waiting lists for necessary medical procedures. This has created an environment in which patients with rare diseases, like cystic fibrosis, are often left without the treatment they need to manage their condition.