



## SAVE NIL'S LIFE!

Save Nil's Life ! I am starting a campaign for Nil who is the daughter of my close friends Anil and Gita. Nil was diagnosed with spinal muscular atrophy (SMA) type 2. In order to have a better future, Nil has to receive a genetic therapy called Zolgensma. Zolgensma costs \$ 2.1 million, with additional expenses the total amount reaches \$ 2.4 million. Zolgensma approval only covers children under 2 years. Nil is 18 months old. We have a fight against the clock. She must receive her treatment in the United States. Below, you can find the story of Nil and her family. Your donations will be greatly appreciated. This campaign is dedicated exclusively to

Nil.-----When you find out you're going to be a mom, everything changes. From that moment on, your life will be completely different, and you start worrying about being able to ensure a good life, a good academic education, the best environment and a more comfortable and safe route throughout your life. And you do it with an unconditional love and you are excited to think about the precious and unique moments to enjoy with your baby. You give birth to your baby and the doctor leaves it in your shaking hands. It is the best feeling in the world. The first contact between you makes you a natural teacher to handle everything that scared you before for lack of experience. You start feeling more secure. And the more you share something with your baby, the more you enjoy being a mother. You already have the answer instinctively of all the questions that you had when you were pregnant. And now is the time to grow together with your baby, cry together, laugh together ...But at one point, even if you have no idea what is happening, something happens and time starts to run in the wrong direction. And that moment all your future plans are shattered, motherhood already has another dimension and your sweet dreams are replaced by a tremendous concern. Because your daughter is diagnosed with a rare disease: Spinal Muscular Atrophy At first you don't want to believe it. Your heart is broken You blame

yourself because you have brought it into the world. Your baby is innocent. On the one hand, you die of regret, your soul hurts, you have the words drowned in your throat but on the other hand the doctors keep telling you that your daughter has to start her treatment immediately. Because every moment, a motor neuron dies. Spinal Muscular Atrophy (SMA) is a neuromuscular disease, which is manifested by a progressive loss of muscle strength that affects the ability to walk, swallow and breathe. And it is the first genetic cause of infant mortality. It is caused by a mutation in the survival gene of motor neurons 1 (SMN1). This gene is responsible for the production of a protein that is critical for the nerves that control our muscles. Without this protein, these neurons cannot function properly and die at any given time. Our daughter Nil is 18 months old. And there is a genetic therapy called "Zolgensma" approved by the US Food and Drug Administration (FDA) for children under 2 years old with a price of 2.15 million dollars. Zolgensma is designed to replace the missing or defective SMN1 gene with a functional copy that produces the SMN protein, thereby improving the function and survival of motor neurons. It seems that Zolgensma can save lives of those who are lucky enough to get it with a single dose treatment. Today Nil can't stand or walk. Unfortunately, we don't have a second to lose. We imagine her walking, running, playing with her friends and we want her to be part of society, feel proud of herself and have a long life. We, as her parents, without knowing that we are carriers of this disease, are broken, it is hard for us to breathe, say something or think ... We need the support of volunteers who can help

Donation



id donate motor neurons for our little daughter. We hope that Nil is one of the lucky  
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-----Ä°ki  
ÄÿÄ±m Ali ve Nihan GÃ¼leÃ§â€™in kÄ±zÄ± Nil GÃ¼leÃ§ iÃ§in bir baÄÿÄ±Äÿ kampanyas



[www.kind.fund](http://www.kind.fund)



[info@kind.fund](mailto:info@kind.fund)