

SAMPLE LETTER - THE HAMMERBARNES FAMILY

To Our Elected Representative,

We ask for your support of the Ensuring Lasting Smiles Act (ELSA). This bill will guarantee insurance coverage of medically necessary treatments for individuals born with an orofacial cleft.

Approximately one in 700 babies are born with a cleft lip or palate (CLP). Despite living in an era and country of progressive thinking and modern medicine, many of these children do not have access to proper care. CLP can create extensive issues related to breathing, eating, speech, and normal development. Yet, there is still a harsh stigma that clefts are “merely cosmetic.” This is systematically represented in the ongoing insurance battles of families with cleft-affected children.

The truth is a person with CLP will likely need multiple surgeries throughout their life to maintain normal function and appearance. Often the first surgery occurs when an infant is only a few weeks old. These procedures continue throughout childhood and into late adolescence. Treatment also requires extensive orthodontics and replacement of any missing teeth.

In the case of dental implants and bone grafts, coverage can be available when performed due to an accident resulting in severe injury but is often denied for congenital abnormalities. To refuse medical access for a child based on CLP, when they could be covered under different circumstances, is blatant discrimination by the insurance companies. ELSA would rectify this loophole. We need your help in passing this bill to defend medical rights for these children.

Our Personal Story:

Alice entered the world with a full head of hair and adorably chubby baby rolls. However, within hours of birth, it became apparent she struggled to eat, even from a syringe. We could tell something was wrong. Over the next few weeks, we spent countless days going to feeding therapy and lactation consultations. Nothing helped.

Her gorgeous baby rolls disappeared as her weight gain slowed. It took her over an hour to finish a single bottle. Each feeding she would cough while trying to swallow, and milk drained out of her tiny button nose like a stream.

At 6 weeks old, Alice choked on milk and stopped breathing for 30 seconds. It was the last straw for us and her pediatrician; we needed to help Alice eat and breathe comfortably. It took a video X-ray, an overnight sleep study, an endoscopy, and multiple weight checks and examinations, but we had an answer: submucous cleft palate. The connective tissue in Alice’s mouth was not fused. She had a hole in her muscles that was covered by a thin layer of skin making it incredibly difficult to detect.

Alice’s first surgery was scheduled for when she turned 9 months old. We spent months watching our daughter struggle with her cleft palate. Daily, she had milk and food enter her nose from the back of her mouth. At night we would hear her wake up gasping for air and coughing. Multiple doctors on her care team recommended continuous oxygen monitoring during sleep. However, our insurance refused to cover an at-home monitor, despite diagnosed sleep apnea and a confirmed cleft palate.

During the agonizing wait for surgery, we collected the evidence of medical necessity required by our insurance. Our care team knew Alice needed help. We knew she couldn’t continue with this condition, but none of that mattered. Her life-changing procedure was contingent on approval from someone who had never met her and was unfamiliar with CLP. Given the stress of an infant requiring major surgery, the last thing we should have been worried about was: *How are we going to pay for this if it’s denied? Will we have to postpone and submit more information? Can she even wait that long?*

We received approval only 4 days before her cleft palate repair. The letter concluded, “If more treatment is necessary, another medical review will be required.” Every surgery, every test, every treatment can be denied as the insurance company sees fit.

Factoring in covered and uncovered aspects of Alice’s care, we will pay close to \$200,000 by the time she is 18. This is unsustainable for the average American family... We ask for your support not just for our daughter, but for every child and family that would benefit from enacting ELSA into law. Please help us eliminate insurance discrimination and ease the financial burden of congenital abnormalities.

Respectfully Yours,

Madison Hammerberg, Alice & Albert Barnes (a.k.a The Hammerbarnes Family)

