



Ensuring Lasting Smiles Act (HR.3277, S.1677) - Impact on Patients with Congenital Anomalies that primarily impacts the appearance or function of the eyes, ears, teeth, mouth, or jaw.

This document shares the personal stories of Americans affected by various congenital anomalies whose health would benefit from passage of the Ensuring Lasting Smiles Act. If people such as these go untreated due to health insurance denials or delays, not only will their overall health worsen, but they will be forced to undergo numerous other costly secondary treatments that may or may not improve symptoms and never truly repair the congenital anomaly or restore bodily function. Initial and ongoing medically necessary treatments for congenital anomalies must be approved to improve the health of Americans like these, and that is what the Ensuring Lasting Smiles Act will ultimately accomplish. But they need your support.



Aidan (Wisconsin): After many years of appointments with specialists at Children's Hospital of Wisconsin, a dental resident and a geneticist diagnosed our son Aidan, with x-linked hypohidrotic ectodermal dysplasia (XLHED). This disease affects Aidan's skin, hair, nails, sweat glands, and teeth. His skin and nails are sensitive, and he gets rashes easily. His sweat glands don't function properly, so he has a hard time regulating fevers and overheats easily. He was born without many of his teeth, and has issues due to his lack of teeth, including speech, swallowing, chewing, and eating. He has had to go through invasive procedures, just to determine that his issues are due to his lack of teeth. When Aidan first started his dental procedures after diagnosis, we were told that since these repairs were medically necessary and needed to be done due to his congenital abnormality, his dental treatments should be covered by insurance. Since his diagnosis, our family has had to fight with our medical insurance for coverage and we soon discovered that very little is covered. Each time we submitted a claim, we have had to appeal several times, and the appeals and denials process for each stage of his treatment is frustrating and unnecessary. Now that Aidan is 20 years old, and most of his dental work needs to begin, we have been told that they have made their final decision to deny his upcoming dental treatments.



Rosie (California): Approximately 1,300 babies born in the US each year have congenital cataracts. My daughter Rosie is one of them. Rosie had surgery at Stanford at six weeks of age with Dr. Scott Lambert. Dr. Lambert has been performing these surgeries for many years and this is his area of expertise (known nationally for his research on congenital cataracts and contact lenses in infants). Following surgery, Dr. Lambert and an infant optometrist fitted Rosie for her first contact lens (glasses are not an option, not powerful enough). My husband and I were shocked to learn these lenses are not covered by insurance (\$200 per lens). The lenses are changed often as the baby's eye grows and vision develops, and the lens can pop out and be lost. Rosie is now 11 months and we have spent over \$4,000 dollars on lenses. To be clear, without these lenses, these babies are blind and have no chance of ever developing normal vision. As Dr. Lambert likes to say - the analogy is denying a prosthesis to an amputee and telling that patient he or she may never walk again. If ELSA passes, ensuring that insurance companies pay for these pediatric lenses, then families would not have to make horrific choices such as their child's vision or putting food on the table.



Ash (North Carolina): Our son, Ash, was born with craniofacial microsomia, a rare congenital anomaly where the left side of his face is underdeveloped, causing unilateral vision and hearing impairment, facial paralysis, and speech challenges. He wears a bone-anchored hearing aid due to conductive hearing loss and a scleral shell to help his bones grow around his little eye. Ash needs ongoing speech therapy to keep up with his peers. Surgical interventions or dental work may be necessary as he grows to ensure he can eat and speak properly. These are all devices, surgeries, and services not guaranteed coverage by insurance providers. We want to provide all of the care we can for Ash without worrying whether an insurance company thinks he deserves or requires this care to live his best life.



Gavin (Montana): We were encouraged to pursue genetic testing and discovered that our son has a rare genetic condition called **Keratitits-Ichthyosis-Deafness (KID) Syndrome**, a form of **ectodermal dysplasia**. The easiest way to explain it is that his entire outer layer—his hair, skin, nails, eye surface, and teeth—is affected. Gavin is **9 years old, profoundly deaf**, and now **legally blind**. He has lost vision in both eyes, suffers from extreme light sensitivity, and lives with a painful skin condition called **ichthyosis**, which causes his skin to be very dry, thick, itchy, and cracked. This condition is so painful at times that it requires the **use of a wheelchair**. He is missing two-thirds of his permanent teeth—he only has about **one-third of them**—and will require **extensive full-mouth dental implants** as he grows older. These missing teeth affect his ability to eat, cause speech distortion, and have serious social consequences, which could impact future employment. Despite these challenges, Gavin is doing incredibly well. He is scoring at the typical level on both educational and language assessments—thanks to the early identification of his hearing loss and the timely intervention services we were able to access. He has undergone numerous surgeries, including **cochlear implants, eye surgeries, skin surgery, and oral surgery**. Thankfully, most of his surgeries have been covered by our insurance. However, we continue to face significant financial

challenges. We spend thousands of dollars annually on therapies and essential items to help Gavin reach his full potential. For example, his vision care requires **special prescription contact lenses that cost \$300 and must be replaced every three months, compounded prescription eye drops and serum tears**, which are made from my own blood to provide moisture and relieve pain. These items have significantly improved his comfort and vision. **Despite having both commercial insurance and Medicaid, none of these critical items are covered.** They are so beneficial that we make difficult budget adjustments to afford them. We are deeply concerned about Gavin's future. The need to **restore his mouth to a fully functional state** is urgent and essential for his health, confidence, and success. The cost of **dental implants** is overwhelming. Please support the **Ensuring Lasting Smiles Act (ELSA)** so that Americans with congenital abnormalities can access insurance coverage for medically necessary treatments. Restoring basic body functions should not be a luxury. Providing this coverage would improve the lives of thousands of individuals—and in doing so, strengthen our educational system, workforce, and economy.



Ally (Colorado): I was born without my right ear, no ear canal and a slightly crooked smile. This rare congenital anomaly is known as Microtia, Aural Atresia and craniofacial microsomia, which affects approximately 600 babies born each year here in the United States. Many families who have a child like me often feel alone and struggle to find the answers they are looking for from their doctors. My family has taken me to all of the medical specialists they were supposed to in hopes of finding the answers we were looking for. Along the way, we have learned about a hearing device, called a bone conduction hearing aid, that I need to help me hear and about reconstructive surgery for making an ear for me so I can simply wear eyeglasses. Now that I am twelve years old, I have needed to have some of my teeth extracted due to the craniofacial microsomia that affects my jaw.

To my family's surprise, we have discovered that many of the medical needs I require are not covered under private insurance. The bone anchored hearing aid that I need to hear better with is often denied by insurers and costs tens of thousands of dollars and will eventually need to be implanted and upgraded every five years (over \$100,000 spent over my lifetime). The surgery I would need to reconstruct my ear will cost well over \$200,000, which I may like to have someday so I can have two ears just like everyone else. The teeth I have had to have extracted and rotated have already cost hundreds of dollars and is not covered by dental insurance (so far \$1,500 spent). There are many other children and adults just like me. Some are missing both of their ears and need two hearing devices or two ears reconstructed and need even more teeth that need to be extracted. My mom says that I can be anything I would be in life, but these necessary things will help me get there! It is important that implantable hearing devices such as bone anchored hearing aids, reconstructive surgeries and teeth extractions are covered by insurance in order to give children like me the opportunity to thrive and live a good life. So many of us have had our medical claims denied by private insurers when they are absolutely needed and are medically necessary. My hope is that kids like me are given a chance to do well in the communities we live in and with passage of the Ensuring Lasting Smiles Act, S. 754, this piece of legislation would help me and so many others live the lives we dream.



Alli (Iowa): “At the age of six, I had a dental visit following a playground injury. All previous dental visits were “normal,” with all 20 baby teeth and routine care appointments. Following a panoramic dental x-ray, my family and I learned that I was missing multiple permanent teeth. The next step was to see specialists. I would travel to the University of Iowa and the University Of Illinois Chicago. These long road trips would range from 4-12 hours round trip to see specialists. Additionally, I had appointments set up with genetics, dermatology, and several other dental specialists. Together, they were able to diagnose me with hypohidrotic ectodermal dysplasia. As for now, I am still missing 18 permanent teeth, but having a diagnosis explains a lot about my childhood. Specifically, it explains my frequent GI issues, inability to eat certain foods, and frequent periods of overheating. I am currently on year two of my first dental implant with a few more in the next couple of years. The cause of my missing teeth is a birth defect that correlates to numerous other health issues. Unfortunately, this treatment is not covered by medical insurance.



Rosie (Illinois): Rosie, who is now 5.5 years old, was born in 2019 at 2:30 a.m. At 4 p.m., we were told she failed the red eye test and that the Pediatric Ophthalmologist was being referred to check her. At 6 p.m., at hardly 18 hours old, we were told she has bilateral congenital cataracts and would require surgery at 6 weeks old. We have no family history of congenital cataracts so she went through extensive testing to rule out infectious diseases, and it was deemed to likely be the result of a genetic mutation. Rosie had her cataracts removed at 6 and 7 weeks old (one surgery per eye), and we were told she likely couldn't see anything except extremely bright lights due to the size and density of the cataracts. At 8 weeks old, she was fitted for her first pair of contacts. We were told that we “may have issues” with insurance paying for them, but we were assured they were medically necessary and the best

course of treatment for her vision development. Over her first 18 months of wearing contacts, her prescription changed 4 times, and we lost many contacts due to fit issues that took some experimentation to resolve. The contacts are \$343 each. At one point, we had an invoice totaling \$3,000 while we were waiting for insurance to respond to our appeals. I spent 1-2 hours a week on the phone for almost 9 months fighting to get the lenses covered. Despite everyone with our insurance agreeing that the lenses were medically necessary and considered prosthetics, it took many levels of appeals and a call into my husband's employer to get them covered. We went through this process for every contact she was prescribed. Rosie had surgery last winter to have lenses implanted into her eye as she was no longer tolerating contacts well. Her doctor opted to choose a lens strength that would work for her eye and vision now, and use glasses to correct her vision as she grows. She will always need corrective lenses. Her glasses are bifocals (reading glasses to allow her to see up close and distance vision to add to the lens in her eye. This will be for her entire life. These glasses may be covered partially by vision insurance but we expect to need 2-3 new pairs every year as her prescription changes; vision insurance covers 1 lens every year and 1 frame every 2 years. We have gone through all of this for the last 5.5 years, and it will always be part of Rosie's life. ELSA would mean we do not have to worry about whether Rosie's necessary treatments will be covered: no more budgeting and planning each year to make sure we can get her what she needs; scouring our house if we do lose a contact because we don't have a backup on hand because of the cost; and setting her up for success for her future. Rosie luckily is developing vision at a normal pace for her age, thanks to early detection and surgery as well as her contacts and glasses and ELSA would make this a much easier process and possibility for many other kids like her.



Lauren (Tennessee): Hi! My name is Lauren. I was born with a bilateral cleft lip and palate, which means I had splits on both sides of my upper lip leading up to the base of my nose, and I was lacking a roof in my mouth. By the time I was 7 years old, I had seven surgeries to help correct my cleft lip and palate. Many of these surgeries were considered cosmetic because they were performed by a cosmetic surgeon and insurance would only cover some—but in some cases none—of the costs. I wore braces just short of ten years and went to speech classes for three years to overcome lisps and compensating pronunciations. At age 17, I had another major surgery which consisted of surgically repositioning my upper and lower jaws and chin to correct a severe underbite and to add support in the upper parts of my face (i.e. cheek area) that I was congenitally lacking. My health insurer initially

deemed the surgery unnecessary and notified me that I would have to pay for it myself. My oral and maxillofacial surgeon pressed back against the insurer explaining that if I did not have this surgery, it would impair my speech that I had worked so hard to correct, my face would slowly concave in and grow more in a “c” shape and my underbite would get progressively worse making it harder for me to eat everyday food. The insurer ultimately agreed to cover the cost of surgery; however, they subsequently denied coverage for a dental-related procedure associated with my condition. Due to the hole that originally existed from the top of my lip to my nose, I had a missing front tooth and needed a permanent prosthetic tooth, or a “dental implant.” I applied to my health insurer to help cover the procedure, but because the placement of my absent tooth was in the front and not a back molar they considered replacement of the front tooth “cosmetic.” Tell me having a front tooth is not essential to securing a job, eating, or having self-esteem? I had to borrow \$13,000 to cover the cost of that procedure. Overall my parents and I have spent \$20,000 to cover the cost of my treatment since birth. While I am beyond grateful that my family and I were ultimately able to pay for the various stages of my treatment, it did not come without ripple effects. The expenses we paid to help me speak, breathe and eat—which have allowed me to go on to become a pediatric nurse—have placed unnecessary financial strain on me and my parents not only in the present, but for the years to come.



Karl (Minnesota): My name is Karl. I was born in rural Minnesota and wasn't diagnosed with ectodermal dysplasia until the age of 5 when my dental challenges became obvious. I have only a few baby teeth and even fewer adult teeth. I received my first set of dentures when I was 5 and they quickly became an amazing tool for “shock value” during my grade school years! As I grew, I needed larger dentures and my parents struggled to get them covered by our medical insurance, despite numerous appeals as the dental needs were a result of my medical condition. During my 20s, my teeth deteriorated and were not viable to support another denture. I had to make a hard decision and I was advised to pursue dental implants at the University of Minnesota.

This was a great decision and the right treatment plan for me. The implants and associated prostheses were both an improvement in function as well as appearance. However, it came with a significant price which I had to pay out of pocket as my medical insurance wouldn't cover it. 10 implants, a fixed removal denture on the bottom and a removal denture on the top cost me well over \$30,000 in 2000. It was a hard decision, but it was the right decision. In my mid-40s, a couple of the implants in my mandible failed. Bone grafting was needed to build up the site for restoration again. They were able to shave off the top margin of the back of my mandible (ramus) to harvest enough material to fill in the defect. It took several months before the bone was ready for a new implant to be placed. I have been advised to replace the implants in the maxilla soon. During this phase, I'll need bone graft material to be placed in my sinus cavities to help anchor the replacement implants since my bone density is abnormal, like many people with ectodermal dysplasia. As you can imagine, I'm not looking forward to this step. My medical insurance does not cover any of the implants or the new dentures that I'll need for my oral restoration even though I work hard and pay my premiums. Please support this legislation so medical insurance companies clearly understand that teeth are not cosmetic and that restorations of congenital anomalies, including dental changes, should be included in their medical plans. Let's get this right so my daughter doesn't have to be fighting for every single tooth. Let's get this right so your daughter, your son, your granddaughter, or your grandson doesn't have to repeatedly read denial letters.