

*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 16 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.



**Emma (New York):** We first saw signs of swelling in Emma's left foot when she was 7 months old, and she wasn't properly diagnosed for 11 more months. Emma was born with Primary Lymphedema in her legs and feet. A rare, progressive, incurable disease with one gold standard treatment, manual lymph drainage paired with medical grade compression garments, to control the swelling enough for her to maintain a normal life. Emma is about to turn 14, and any time we've requested these services we have had to fight insurance. Our private insurance covered so little, that we had to move her to state insurance. This sets major limitations for us because she can only be seen in NY when the best pediatric lymphedema care near us is in Boston.

In the beginning of her diagnosis, we went into medical debt just to give her the basics so she could simply learn to walk. Emma is prone to cellulitis infections that oftentimes result from lack of proper medical compression garments. At almost 14 years old, she's had 12 infections in her life, six of which required hospitalization, and she was once steps away from becoming septic. This is her life due to complications of lymphedema. As a child, she grows so fast—the two pairs of garments she is granted through her insurance isn't enough for a year. Compression garments are the most basic of care for a lymphedema patient, covering the cost will save so much money in the long run. If lymphedema patients don't have continuous access to proper compression, they will wind up in the hospital. Throughout the years we've learned about insurance appeals and how to fight for our child. The point is, we shouldn't have to. These kids are rare; their life is hard enough. Insurance companies need to stop finding loopholes to claim ignorance in providing families with basic necessities to save their children's lives.



**Gavin (Montana):** I am advocating for my son Gavin because he has several needs in which the Ensuring Lasting Smiles Act would help him reach his full potential and have normal body function. When my son Gavin was only a few weeks old we discovered he had a profound hearing loss. This was caught during his newborn hearing screening, which is a mandated screening in all 50 states. As we started the process to get him hearing aids I was distraught to find out our insurance would only cover a small portion of the \$5,000 needed for hearing aids.

After speaking to many families with deaf/hard-of-hearing children I learned it was very common for insurance companies to not cover hearing aids or any audiology services. Even though state-funded programs like Medicaid cover these needed services. There are mandates in place that we screen newborns for hearing loss because a delayed diagnosis can have severe consequences on communication, education, future employment, and social-emotional skills. But we have no mandates in place that these children will receive the services they need. Please consider these facts:

- For children with hearing loss to develop speech and spoken language, amplification devices are a medical necessity. Hearing loss is considered a developmental emergency. It requires early intervention to prevent permanent delays.<sup>1</sup>
- Hearing aids can cost \$6,000 per pair and must be replaced every 3-5 years. This is an expense of over \$40k by the time a child reaches age 21.
- Children who do not receive early intervention for hearing loss cost schools an additional \$420k and are faced with overall lifetimes costs of \$1 million in special education, lost wages, and health complications.

The financial impact of untreated hearing loss is huge. For families who choose spoken language for their deaf/hard-of-hearing child, this cost is often left to them. For families who can't afford to pay out of pocket these children suffer greatly. As does the education system, workforce, and economy in our country.

We were encouraged to have genetic testing done and found that my son has a rare genetic condition called keratitis ichthyosis deafness syndrome, a form of ectodermal dysplasia. The easiest way to explain it is his entire outer layer is different. His hair, skin, nails, eye surface, and teeth are all affected. He is profoundly deaf, has lost his vision in the right eye, suffers from severe light sensitivity, is missing 10 permanent teeth, suffers from dental cysts that destroyed six permanent teeth, and has a painful skin condition. The skin condition, called ichthyosis, causes his skin to be very dry, thick, itchy and cracked and requires the part-time use of a wheelchair. He has had multiple surgeries due to his condition, including cochlear implants, eye surgeries, skin surgery, and oral surgery. Fortunately, our insurance has covered the majority of his surgeries. We have personally spent a large amount of money every year on therapy and items Gavin needs to reach his full potential.

Despite all his challenges, Gavin is doing very well. He is scoring at the normal level on educational and language assessments. This is because we were able to discover his hearing loss early and receive the services he needed. I am very worried about the future as we need to restore his mouth to a fully functioning state. Right now Gavin is 6 years old and missing all his front teeth, this is typical for children his age, but as he ages, missing front teeth and back teeth will be very abnormal. It will cause difficulty eating, speech distortion, and have strong social consequences, which could lead to employment challenges. I don't know how we will afford 12 dental implants. Please support ELSA so that Americans with congenital abnormalities will have health equity. Having insurance coverage for services that restore body function will improve the lives of thousands of citizens, which will improve our economy and educational system.

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<sup>1</sup> White, Karl R. and Antonia Brancia Maxon. "Universal screening for infant hearing impairment: simple, beneficial, and presently justified." *International journal of pediatric otorhinolaryngology* 32 3 (1995): 201-11.



**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.



**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 to 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 6.5 years old, Alli visited her dentist after a playground injury to her top teeth. She had all twenty of her baby teeth and all routine cleaning exam visits had been “normal.” Our dentist took a panoramic dental x-ray as part of her treatment; upon reviewing the films, he shared the words ectodermal dysplasia. We had never heard of ectodermal dysplasia, but instantly knew it would become a big part of our lives. We spent the coming months and years commuting 240 miles, round trip, to University of Iowa Hospitals and Clinics. Appointments with genetics, dermatology and several dental specialists resulted in a clinical diagnosis of hypohidrotic ectodermal dysplasia (HED).

It was identified that Alli had 12 permanent tooth buds, which meant she would be missing 20 adult teeth. Learning more about HED, we finally had clarity about her gastrointestinal issues, inability to eat certain foods, frequent overheating, pigment issues with her skin, brittle nails and dry hair. Currently Alli is two years in on her second set of orthodontic braces, as soon as her braces are ready to come off, she will be ready for her first dental appliance. This will not be covered by our medical insurance even though the cause of her missing teeth is a birth defect and causes several other health related issues.



**Rosie (Illinois):** Rosie, who is now 2.5 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 go through this process with every contact she is prescribed, and we have opted to pay out of pocket and order from online vendors to control the process. Rosie also wears bifocal glasses, as of last fall, to see close up (her contacts are for far vision) and are also medically necessary. We pay for these out of pocket because our insurance won't even consider paying for them. We've opted to add her to our vision insurance in hopes that even one contact will be paid for but know that we will have to jump through hoops to get them covered. We have gone through all of this for the last 2.5 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 ELSA would make this a much easier process and possibility for many other kids like her.



**Ash (North Carolina):** Our eight-month-old son, Ash, was born with oculo-auriculo-vertebral syndrome, a rare congenital anomaly that affects his face and his heart. It can present itself in different ways, but for Ash, he has hemifacial microsomia, where the entire left side of his face is underdeveloped, and his heart has a right aortic arch. He has microtia and atresia (no left ear or ear canal), as well as microphthalmia and an anterior segment dysgenesis (a small left eye, and undeveloped cornea and iris). He also has facial palsy, an underdeveloped soft palate, and the left side of his jaw and cheekbones are smaller than the right side.

He is still young, and all interventions so far have been non-surgical, but we know that as he gets older and his bones grow he will need reconstructive and corrective surgeries. If he has hearing capabilities on his left side, he will need inner and outer reconstruction surgery to give him a left ear and restore hearing to that side. He will also need surgeries to elongate his jaw and dental reconstruction to ensure his teeth are not crowded and he can speak and eat without discomfort. This is on top of possible eye surgery, as sometimes microphthalmia can result in an eye needing to be removed, and his heart defect comes with the possibility of surgery to ensure a vascular ring does not interfere with his breathing.

When Ash was first given the diagnosis of hemifacial microsomia we were referred to a geneticist who recommended more in-depth testing to rule out any other genetic anomalies. Shortly after receiving the results we got a letter from our insurance company saying we were denied coverage for the test, as it was deemed "not medically necessary." We are currently in the appeal process for this claim, and view this experience as a telling example of what to expect in the future regarding our son's healthcare needs and what is deemed medically necessary. We want to provide all of the care we can for Ash without having to worry whether an insurance company thinks he deserves or requires this care in order to live his best life.



**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 under bite 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 under bite 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.