Testimony of Mr. Kevin G. Koser, Patient Advocate,
On Behalf of the National Foundation for Ectodermal Dysplasias,
Supporting the Subcommittee on Health of the Committee of Energy & Commerce
Hearing on “Legislation to Improve Americans’ Health Care Coverage and Outcomes”
Wednesday, January 8, 2020 at 10:00am
2322 Rayburn House Office Building

Good morning, Chairwoman Eshoo, Ranking Member Burgess, and distinguished Members of this Committee. Thank you for the opportunity to speak with you this morning about a cause and bill that are very close to my heart. My name is Kevin Koser, and I live in central Virginia with my wife, Rachel, and two sons, Kannon (4) and Kage (11-mos). On a volunteer basis, I serve as a Co-Chair of the National Foundation for Ectodermal Dysplasias’ Family Advocacy Committee. But my most important title is father and concerned parent. Our son, Kannon, who is sitting in the audience today, was diagnosed with a congenital anomaly called Ectodermal Dysplasia, which requires extensive, medically-necessary treatments so he can live a long, productive, and healthy life.

I am here to ask for your support in advancing **H.R.1379, the Ensuring Lasting Smiles Act**, on behalf of the estimated 3-4% of Americans just like Kannon who are diagnosed with a congenital anomaly, commonly known as a birth defect. As of Monday, January 6, 2020, the House bill had 261 bipartisan cosponsors (186 Democrats and 75 Republicans), including 21 members of this Subcommittee and 33 members overall from the Energy & Commerce Committee. The identical Senate bill, S.560, had 37 bipartisan cosponsors (19 Republicans and 18 Democrats).

What is the Ensuring Lasting Smiles Act?

This bipartisan, bicameral bill will ensure that all private group and individual health plans (including self-funded plans regulated by ERISA) provide coverages for Americans who are born with congenital anomalies and then require medically-necessary treatments to restore function to missing, poorly functioning, or non-functioning body parts that resulted directly from the diagnosed anomaly. It further clarifies the inclusion of adjunctive dental, orthodontic, and prosthodontic services for congenital anomalies that impact the mouth, teeth, and oral cavity.

The intent of this bill might seem like commonsense. It is. Health insurance should approve claims for medically-necessary treatments of congenital anomalies. In many cases, that is happening, especially when you think of more well-known anomalies like congenital heart defects, missing or defective limbs, or neural tube defects like Spina Bifida.

However, the problem is that health insurance companies systematically deny or delay medically-necessary treatments for Americans diagnosed with a host of other congenital anomalies, such as those that affect the teeth, mouth, and oral cavity, like Ectodermal Dysplasia. Insurers deny treatments for these congenital anomalies by calling the treatments “cosmetic” and “not medically-necessary,” despite an official medical diagnosis and physician-approved care plan. Or insurers state that the requested procedures are “not covered benefits” because they appear to be dental-related, even though they are directly linked to an underlying medical condition.

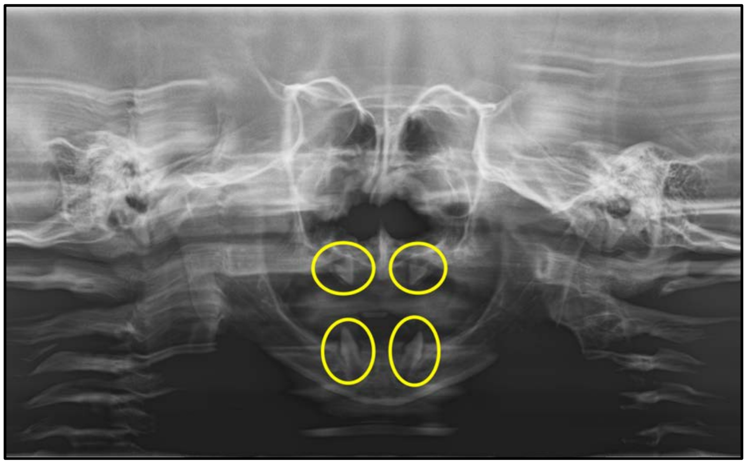
Why Did I Get Involved in This Effort?

My family's story serves as an example of the struggles that Americans with similar diagnoses face across the country. Kannon was born in September 2015. It was—and still is—one of the happiest days of my wife's and my life. There were no signs that anything was wrong. But it is important to understand that not all congenital anomalies present their symptoms immediately at birth. At a routine dermatology appointment when Kannon was 9-months old, the doctor recognized some of the clinical traits of Ectodermal Dysplasia in our son Kannon: his hair was sparse and platinum white; his skin was prone to rashes; he did not sweat; and there were no signs of teeth. Genetic testing was conducted when Kannon was 1-year old, which confirmed the diagnosis.

Ectodermal Dysplasia is a congenital anomaly that affects the development of the hair, skin, sweat and saliva glands, teeth, and sometimes other body parts, depending on the specific diagnosis. There are at least 180 known variants of Ectodermal Dysplasia—some are more severe and impact limb development, eyesight, or in some cases even lead to death due to infections caused by severe skin erosions. These traits result in a lifetime of medical needs across multiple medical disciplines.

But it is specifically the issues with the teeth, oral cavity, and bone structures supporting the teeth that has galvanized our families to lead the charge in advocating for the Ensuring Lasting Smiles Act. Teeth may be missing or completely absent; their eruption is significantly delayed; the enamel is weak, making the teeth brittle; they will often be conical in shape instead of squared; and the lack of teeth causes the jawbone and gum line to recede and decay.

Kannon is now 4-years old and just recently sprouted his first tooth. X-rays indicate that he only has four (4) total teeth, which are circled in yellow in the image below. A child without Ectodermal Dysplasia typically grows 20 teeth, and an adult grows between 28-32 teeth.



Please put yourself in Kannon's shoes. Imagine the drastic impact this would have on your health and quality of life:

- Your diet is severely restricted—Kannon's diet is limited to soft foods like sliced fruits, hummus with dissolvable crackers, PB&J sandwiches, and pancakes. He is physically unable to eat nutritious foods like fruits or vegetables that are crunchy, and he is unable to eat protein-rich foods like meats or nuts that require teeth to chew.

- Your limited diet results in a lack of proper nutrition, which is the foundation for cognitive and physical development, so you'll likely need daily supplements or meal-replacement products.
- Even with a diet of soft or pureed foods, you'll be prone to choking because you can't chew and have reduced saliva, which is a catalyst for proper digestion.
- Your inability to chew results in gastrointestinal (GI) issues, such as constipation, irritable bowel syndrome; cramping; or ulcers. Otolaryngologists (or ENT) and GI specialists will conduct swallowing studies, and you'll be put under general anesthesia so they can examine your stomach and digestive tract with a scope.
- You struggle to speak properly, requiring speech evaluations and years of speech therapy.
- As your jawbone and gum line decay and recede from the lack of teeth, you require multiple, complex bone grafting surgeries to reconstruct your jaw and facial structures.
- The list of secondary medical issues goes on. You'll need a team of physicians and specialists across multiple disciplines, all of whom tell you that your health is suffering because you don't have a mouth full of functioning teeth.

While there is no cure, and while everyone's medical care plan varies due to differences in how the traits present themselves in the patient, there are several common treatments that are medically-necessary to manage these issues. These treatments are not optional; they must be conducted to restore function to the mouth and for the patient to live a healthy life.

- First, prosthetic teeth (or dentures) starting between the ages of 2-5 and replaced every 1-3 years as the mouth grows.
- Second, surgeries to reconstruct and replace the decaying jawbone and gum line through grafting. The bone is necessary for dentures to rest upon and for our 3rd common treatment, dental implants, to be installed.
- Permanent dental implants are typically installed once an individual's mouth stops growing, usually around age 20. These also help prevent further bone decay through oseointegration.

Last Christmas, Kannon asked Santa Claus for teeth so he could "chomp big bites" of food like other kids in his class. Think about that. Our then 3-year old little boy—who loves dinosaurs, dragons, and superheroes—asked for *teeth* for Christmas. We began pursuing dentures for him, in accordance with a treatment plan established by oral and maxillofacial specialists. Imagine our heartbreak when our health plan told us that "any services relating to his teeth or intra-oral structures supporting the teeth are not a covered benefit," even though the same policy has mandated coverages for medically-necessary treatments of congenital anomalies. This will force us to pay for his medically-necessary treatments 100% out-of-pocket.

We are not alone.

Aidan—a 14-year old boy from Wisconsin—was first told that his oral treatments only served a "cosmetic" purpose and therefore must be paid for 100% out-of-pocket. At a future critical stage in his treatment plan, and after a Medical Review Board agreed that his treatments were medically-necessary, his father's employer, who maintains a self-funded health plan, changed the language of the denial, then stating that the treatments were dental and therefore “not covered benefits.”

Alli—a 13-year old girl from Iowa—was told that her recent surgery to install temporary implants is “not a covered benefit.” The two implants are absolutely critical in creating anchors for her to receive properly fitted dentures so she can eat and speak properly.

Karl—a 47-year old father from Minnesota—has fought for decades with his health insurance company about the medical necessity of a fully functioning mouth. He has been denied coverage for treatment of his Ectodermal Dysplasia when that same insurance policy stipulates that accidental injuries to the mouth are covered benefits. This is a fight he’ll have to continue, not only for himself, but also for his daughter, who has the same condition.

The stories are endless, and they come from all across the country. This is certainly not limited to the Ectodermal Dysplasias community. Dozens of other organizations, representing multiple congenital anomalies and medical professions, have joined this effort too. A full list of supporting organizations is attached to this testimony.

What Are the Physical and Financial Impacts of Claims Denials and Delays on Families?

The patient’s health suffers when insurers deny or delay claims for medically-necessary treatments that are meant to restore bodily function as a result of a congenital anomaly. These treatments are not optional. Beyond the physical impact of these denials and delays, the financial burden of paying for this medically-necessary care 100% out-of-pocket is substantial and varies depending on the unique medical care plan that is tailored to fit the individual patient’s medical needs. The National Foundation for Ectodermal Dysplasias estimates that some individuals will pay upwards of $150,000 out-of-pocket in their lifetime just for medically-necessary treatments related to the mouth, teeth, and oral cavity.

Coverages for congenital anomalies already exist in an overwhelming majority of private health plans, but insurance companies bypass those clauses by using the aforementioned “cosmetic” loophole or inappropriately applied “dental exclusion.” As a result, our families must make tough and often life-altering financial trade-offs by trying to save money for teeth instead of college or retirement, or taking out second mortgages, to pay for these medically-necessary treatments, even though we are already paying for congenital anomaly coverages through our health plan’s premiums. So why are health insurers bypassing congenital anomaly clauses within their own policies? Why are health plans separating the mouth and teeth from the rest of the body when directly related to an underlying congenital anomaly?

Moreover, the need for (and costs associated with) secondary treatments—which result directly from the initial denials and delays—would drastically be reduced or even eliminated if health plans appropriately approved claims for medically-necessary treatments such as dentures, reconstructive surgeries, and dental implants. Often, the cumulative cost of these secondary treatments far exceeds the cost of the initial medically-necessary treatment. For example, approving the initial medically-necessary claim for prosthetic teeth would very likely result in an improved ability to chew (reducing or eliminating the need for ENT and GI specialists to conduct swallow studies or endoscopies), improved nutrition (reducing or eliminating the need for appointments with nutritionists who prescribe nutritional supplements, medications, or meal-replacement products), improved speech (reducing the need for speech evaluations and therapy), and improved self-esteem and mental health (reducing the need for psychotherapy appointments with mental health professionals). Approving the claims for medically-necessary treatments would not only improve the health of the patient, but also reduce costs to the patient and insurance company.

What is the Foundation for this Bill?

The foundation of this federal bill rests on two key points. First, all 50 U.S. states have congenital anomaly statutes, and these are usually written in open-ended ways as if all medically-necessary treatments for all medically-diagnosed congenital anomalies are supposed to be covered health benefits. These state laws apply to all private group and individual health plans issued in that state, otherwise known as “fully-insured” health plans. (“Self-funded” health plans, which are regulated at the federal level, do not have to abide by state laws.) Second, and as previously stated, an overwhelming majority of private health plans—both “fully insured” and “self-funded” plans—include benefits for medically-necessary treatments of congenital anomalies.

Even so, health plans continue to use loopholes and inappropriately applied dental exclusions to bypass the state laws and congenital anomaly clauses that exist in most health plans.

Closing Statement

Our families and children are already dealing with so much due to the diagnosis and physical impact of a congenital anomaly. Fighting health insurance denials and delays—for treatments that are medically-necessary and tied directly to a medically-diagnosed congenital anomaly—causes unnecessary, additional physical suffering for the affected individuals who absolutely require the treatments in order to live a healthy life.

We must close the loopholes and unintended coverage gaps that health insurers use to bypass state congenital anomaly laws and their contractual obligations to approve claims for medically-necessary treatments of congenital anomalies. That is exactly what H.R.1379, the Ensuring Lasting Smiles Act, will do.

On behalf of Kannon and all of our families, thank you for your time and for listening. And thank you to Congressman Peterson, Congressman Riggleman, Senator Baldwin, and Senator Ernst for introducing this bill. It is our hope that you will do everything in your power to pass this important bill for Americans born with congenital anomalies.

Attachments:

1. Ectodermal Dysplasia Patient Stories
2. List of Organizations Currently Supporting the “Ensuring Lasting Smiles Act”
3. Support Letter from the National Foundation for Ectodermal Dysplasias, 2 January 2020
4. Support Letter from Members of the “Ensuring Lasting Smiles Act” Coalition, 3 January 2020

Attachment 1. Ectodermal Dysplasia Patient Stories

These stories are representative of the Ectodermal Dysplasias community that has faced significant health setbacks when trying to get medically-necessary treatments to restore function to the mouth and teeth due to a congenital anomaly.

Becky Abbott, M.P.H., on behalf of her son, Aidan Abbott (14-years old), of Wisconsin. My son Aidan was born on January 17, 2005 with health issues and was kept in the hospital for four days. Since birth, he has had chronic health issues and was seen by medical professionals and specialists often. At around the age of 2-3 years old, we noticed that Aidan was missing several of his teeth and we took him to our family dentist for an evaluation. The family dentist referred us to Children’s Hospital of Wisconsin, due to the complexity of Aidan’s congenital anomaly. During our first appointment with a pediatric dentist at Children’s Dental Center, the dentist mentioned that she believed Aidan had a rare disorder called Ectodermal Dysplasias, due to his missing teeth and health issues, and recommended that he be seen by a geneticist.

Our family made an appointment with the geneticist, and they confirmed the dentist’s diagnosis of Ectodermal Dysplasia. Both the pediatric dentist and geneticist noted that Aidan’s treatments and procedures to repair his congenital anomaly and replace his missing teeth would be covered under our health insurance. The dentist at Children’s recommended that Aidan start out with a lower prosthetic to help with chewing and his speech. That prosthetic was denied on the basis that it served a “cosmetic” purpose. After going through the denial and appeals process, our insurance approved Aidan’s first prosthetic and related dental work. However, in the meantime, Aidan developed severe speech, swallowing, and choking issues. Aidan was unable to communicate with family, classmates, or teachers and was referred to a speech therapist and subsequent speech therapy that lasted nearly 3.5 years. He also developed swallowing and choking issues and was referred to specialists at Children's, where he underwent a swallowing study, and endoscopy to determine the underlying issue that was causing him to have issues swallowing. Our family practitioner also prescribed Prilosec, as he believed Aidan had GERD. The endoscopy determined that Aidan did not have GERD and the medication was discontinued. All of his health issues were related to his missing teeth. His diet was altered, and he no longer wanted to eat whole foods for fear that he would choke on his food, as he had done several times in the past. We started supplementing his meals with food pouches and Pediasure to ensure that he was receiving the nutrients he needed. As Aidan refused to eat many of the solid foods that he was recommended at that age, he also developed chronic constipation and severe stomach pain. He was referred to a gastroenterologist who prescribed constipation medication to help relieve his symptoms. These developing issues lasted for several years.

Once his lower denture was placed, he began to develop better speech, and he was able to chew better. He was still hesitant to eat solid foods for quite some time, and it took several years for him to be able to chew slowly enough and feel confident that his food would be digested properly without choking. We believe that most of these issues could have been avoided if the prosthetic was approved in a timely manner.

Over the next several years, Aidan went back to his dental specialist for frequent checkups to determine what the next steps of treatment would involve. At one of his follow-up appointments, the dentist mentioned that, due to Aidan’s missing teeth, his two front teeth had erupted too far and were too long. They also noted that the same teeth were at risk for trauma. They recommended that Aidan have orthodontia to move teeth into place to protect those front teeth from risk of trauma. The coverage for that treatment was denied.

On a follow up appointment, his dental specialists believe he should have a frenectomy to remove the tissue that had grown in between the two teeth, as well as four teeth removed to make way for other teeth to be moved into place to protect his two front teeth. The frenectomy was approved, but the subsequent removal of the four teeth were repeatedly denied. The insurance company gave different reasons at different stages of the appeals/denials process and ultimately denied the treatment, saying that the treatment was needed for his upcoming orthodontia, even though the service did not include the use of orthodontia.

Since Aidan's initial prosthetic, we have had to fight insurance for most of his complex treatments. His case has gone to a third-party medical review board. The review board determined that his treatments are medically necessary and that the suggested treatment plan is suitable for the repair of Aidan's congenital anomaly. Even so, our insurance provider used every loophole available to continue to deny his services. One of his initial treatment plans was quoted at approximately $3,080. Since Aidan did not receive that treatment in a timely manner, his treatment plan was forced to change, and the cost of the new treatment has increased to $6,180. Each time his treatment is delayed, he develops new issues and requires additional treatment. His jaw needs to be leveled and aligned, and he has had numerous follow-up appointments, almost weekly, to make adjustments and changes to his dentition.

This is just the start of Aidan's complex treatments, and these treatments will continue for the rest of his life. As Aidan's jaw continues to grow, he will most likely need bone grafting and implants. Our medical insurance policy includes a congenital anomalies clause that includes coverage for the repair of congenital anomalies. The state of Wisconsin also has a state statute that covers the repair of all congenital anomalies from the time of birth. However, our insurance plan is self-funded and federally regulated. Therefore, our plan does not need to adhere to state statutes. Our health insurance company has repeatedly asked for supporting documentation, but no matter how much information we provide from his team of physicians, all of which indicates that his treatments are medically-necessary and required to repair his congenital anomaly, they are still denied.

Jennifer Steele, on behalf of her daughter, Allison Steele (13-years old), and son, Bennett Steele (4-years old), of Iowa. Living with Ectodermal Dysplasia is part of our everyday life. We have two children, Alli (13) and Bennett (4), who are affected. Alli was diagnosed at age 6, and Bennett was diagnosed at age 4. Two of the largest concerns are their inability to sweat and their missing teeth. We have found ways to adapt and control overheating through various cooling products and methods. Their health and smiles mean everything to us, as we want nothing more than our kids to be healthy and happy. We live everyday with Ectodermal Dysplasia, yet it doesn't stop us from enjoying and loving each day.

Missing teeth makes it very challenging to chew food, and a lack of saliva production makes it easier to choke on food. Nutrition is a major concern and reality that we live with daily. Proper nutrition is directly linked to overall health and growth in children. Lack of teeth also causes the jawbone to deteriorate. As a result of missing teeth, Alli has had several procedures, including swallow studies, an upper endoscopy (or EGD), along with frequent medical appointments and tests by several specialists in an attempt to diagnosis and treat her severe GI symptoms that kept her on the verge of failure to thrive for several years due to her abnormal oral development. These tests and medical appointments could have been avoided with proper treatments, by improving her ability to initiate the digestion process in her mouth, like you experience each time something enters your mouth. She only has one molar, which results in an inability to properly mash or chew food. She is limited on what she can eat, and the foods that are the most difficult are the healthy foods, like vegetables and meat. In the next 9-12 months, she will be ready to be fitted for her first partial denture. Who at the age of 13 wants to wear a denture? Alli does. She wants to have enough teeth in her mouth that she can easily chew her food for the first time in her life. Missing teeth also has had a negative impact on her mental health and self-esteem. She wants to be confident with her smile. This medically necessary process will be a 100% out of pocket cost, even though this is a result of a birth defect.

Alli received her first set of braces at age 7, due to her teeth twisting, turning, and moving into the space that is available in her mouth due to missing teeth. We traveled 260 miles round-trip to the University of Iowa every 3-6 weeks for 4-5 months because there wasn't a local orthodontist that was comfortable with treating her. In December 2016, Alli began the process for her second set of braces, this time requiring only 52 miles round-trip from home to Ankeny, Iowa. Due to the complexity of her dental condition, we make the trip to the orthodontist every 3-4 weeks. She will likely require one more set of braces before she moves on to the more permanent solutions of bone grafting for her jaw and dental implants, which will begin between ages 18-21. Alli currently sees a family dentist in West Des Moines, IA for routine cleaning and care, an orthodontist in Ankeny, prosthodontist at University of Illinois – Chicago, and a pediatric dentist in Iowa City.

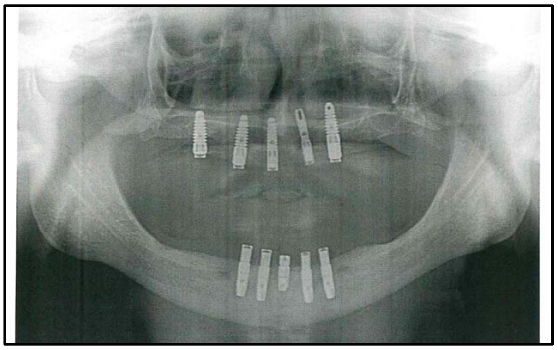
On December 10, 2019, Alli had two temporary dental implants surgically placed in her lower anterior jaw to be used as anchors, since she doesn't have posterior teeth to use for anchorage, to correct her deep overbite and to properly make room in her mouth for the partial denture. This will also assist in correcting her crossbite and allow her to improve her ability to chew. Even though we live in the Des Moines metro area, there is not an oral surgeon that is in-network for our medical plan. We had the oral surgeon's office submit a "gap coverage request" to United Health Care in an effort to facilitate Alli's care. We were notified by our UHC Advocate that a prior authorization would be needed. The advocate reached out to the oral surgeon's office and assisted with the gap request and prior authorization. A few days prior to the December 10th surgery, we were notified by the oral surgeon's office that the prior authorization was denied as "not a covered benefit." As this was a medically-necessary surgery for Alli, we went ahead with the surgery as planned, paid $1,200 out-of-pocket, and submitted an appeal on the denied prior authorization. The claim was still submitted to our medical plan, yet it hasn't completed the review process. According to our Advocate, the claim is pending additional information from the provider's office. The outcome at this time is unknown. We plan to utilize our appeal options that our medical plan allows in an effort to obtain coverage.

Without closing the loopholes that insurance companies use to deny claims, such as "not a covered benefit" or "cosmetic," we are paying 100% out-of-pocket for our children's medical needs instead of saving money for their college tuitions or to properly invest in our retirement.

With Bennett's recent diagnosis, we currently don't know what to expect for his treatment plan. We will have frequent appointments with the specialists at the University of Iowa who are familiar with Alli, and monitor his health as he grows, and then develop a plan for his missing teeth that is age- and developmentally-appropriate for him. Our family is fortunate to have dual incomes working for great companies. Despite this, we are facing out-of-pocket expenses that could exceed our annual salaries. We need your help to make sure that families like ours, and others living with congenital anomalies have the coverage they need to live healthy and fulfilling lives. When you have a smile that you can be confident about, you can change the world! We need your help.

Karl Nelsen, PA-C, MS (47-years old), on behalf of himself and his daughter, Samantha Nelsen (9-years old), of Minnesota. My daughter, Samantha (9-years old) and I both have ectodermal dysplasia. I have been fighting for medical insurance coverage for my oral restorations my entire life. I was born with only a few baby teeth and even fewer adult teeth. I received my first set of dentures when I was 5-years old and required a new set every 2-3 years as my body grew. My parents applied for coverage through our health insurance and received denials over and over again to cover my dental prosthetics. As you can imagine, this is a stressful process, both emotionally and financially.

As I reached my 20s, my adult teeth began to fail, my dentures were not well anchored, and I had to make a major decision in my life. I pursued dental implants at the University of Minnesota. I had bone grafting, 10 implants surgically placed into my mandible and maxilla (which can be seen in the image below), and a new set of dental prosthetics made in order to restore my function and appearance. During the 1990s, this cost me approximately $30,000 out-of-pocket as my insurance company denied the restorative treatments on the basis that it was dental and not health-related, even though this work is clearly a restoration for a congenital defect, which was supposed to be a covered benefit.

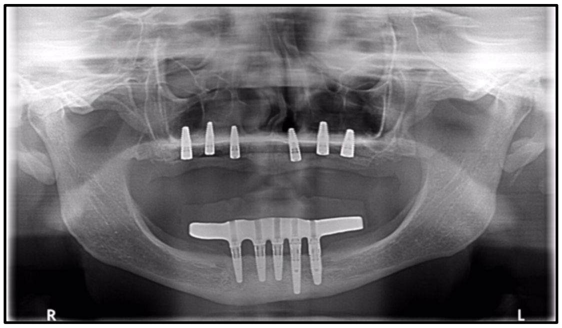


I recently collected estimates for the same work to be done. This same process is now approximately $70,000, which again would be an out-of-pocket expense for a restoration of my congenital changes.

I went approximately 20 years without being active with the National Foundation for Ectodermal Dysplasias until the birth of my daughter, Samantha Grace Nelsen, who is also affected. She is currently 9-years old and will only have a few adult teeth. She will also require dental implants just like her dad. So, the cycle will begin again. Another generation fighting with their insurance companies to get their congenital defects restored.

I believe the success of this bill is entrenched in education. One would think that medical insurance companies provide coverage for congenital defects. For the most part, they do, but our community is caught in the middle since our congenital defect affects oral structures. Thus, they automatically deny claims for our medically-necessary treatments. This is wrong, and we need to close the loopholes that insurers use to deny treatments of congenital anomalies that affect the mouth and teeth.

Julie Claeys, on behalf of her son, Carver Claeys (24-years old), of Michigan. Our son Carver is now 24 years old and completing dental implants after his whole life of wearing dentures starting at age 2 and needing a new set as he grew every two years. In order to obtain implants, Carver had to have bone taken from his hip and implanted into his jaw in order to hold implants in place to prepare for new permanent dentures. An x-ray of his mouth with the implants is included below.



We have paid more than $100,000 out-of-pocket because of denied claims even though our insurance plan stated that they covered medical necessity and birth defects. Congenital anomalies are supposed to be covered by our plan yet our self-funded health plan denied claims. Carver's new set of permanent dentures are billed at a cost of $40,000. He cannot eat or live healthily without these dentures that adhere to his implants. His implants are absolutely medically necessary.

Christine Gottschalk, on behalf of her son, Henry Scott (6-years old), of Washington, D.C. Our son, Henry, has Hypohidrotic Ectodermal Dysplaysia, which is a congenital anomaly. Henry is giggly, tells elaborate tales about fire breathing dragons, and loves to roll down hills with his friends. He also needs teeth. One of Henry's symptoms is anodontia, or the absence of teeth. The lack of teeth impacts his nutrition, speech, and self-esteem. Recently, Henry got his first dentures, and over his lifetime, he will require complex corrective surgeries for normal function. None of the care has been approved by our health insurance. Our claims are automatically denied, and we are forced to cover these expenses out of pocket. My husband is a disabled combat veteran, and our family relies on my income and insurance for Henry's care. This means tough financial trade-offs for our family. We are saving money for teeth and other medically-necessary oral treatments instead of college and retirement, even though our insurance policy has mandated coverages for medically-necessary treatments of congenital anomalies, or when caused by an accident or illness.

Attachment 2. List of Patient and Physician Organizations Supporting the "Ensuring Lasting Smiles Act"

(In Alphabetical Order)

1. Academy of General Dentistry
2. American Academy of Dermatology Association
3. American Academy of Facial Plastic & Reconstructive Surgery
4. American Academy of Neurology
5. American Academy of Oral and Maxillofacial Pathology
6. American Academy of Oral and Maxillofacial Radiology
7. American Academy of Pediatric Dentistry
8. American Association of Oral and Maxillofacial Surgeons
9. American Association of Orthodontists
10. American Association of Women Dentists
11. American College of Prosthodontists
12. American College of Surgeons
13. American Dental Association
14. American Society of Dentist Anesthesiologists
15. American Society of Maxillofacial Surgeons
16. American Society of Plastic Surgeons
17. Bridge the Gap – SYNGAP Education & Research Foundation
18. CCD Smiles
19. Children's Hospital of Wisconsin
20. Colorado Rare
21. Costello Syndrome Family Network
22. Dermatology Nurses' Association
23. Derma Care Access Network
24. EveryLife Foundation for Rare Diseases
25. FACES: The National Craniofacial Association
26. Foundation for Ichthyosis and Related Skin Types, Inc. (FIRST)
27. Genetic Alliance
28. International Pemphigus and Pemphigoid Foundation
29. M-CM Network
30. March of Dimes
31. Moebius Syndrome Foundation
32. National Foundation for Ectodermal Dysplasias
33. National Organization for Rare Disorders
34. Noah's Hope – Hope4Bridget
35. Operation Smile
36. Pathways for Rare and Orphan Studies
37. Project Accessible Oral Health
38. Rare & Undiagnosed Network
39. rareLife Solutions
40. Soft Bones: The US Hypophosphatasia Foundation
41. SunnyStrong

42. The APS Type 1 Foundation Inc.
43. The Marfan Foundation
44. The Sturge-Weber Foundation
45. Usher 1F Collaborative
46. Virginia Council of Nurse Practitioners

Attachment 3. Support Letter from the National Foundation for Ectodermal Dysplasias

nfed
Supporting you. Supporting each other.
NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS

January 2, 2020

Dear Members of the Energy and Commerce Committee,

The National Foundation for Ectodermal Dysplasias (NFED) is the only patient advocacy organization in the United States dedicated to individuals who are affected by rare genetic disorders classified as ectodermal dysplasias. The NFED's mission is to empower and connect individuals touched by ectodermal dysplasias through education, support, and research. The NFED has been advocating for individuals affected by ectodermal dysplasias and all rare disorders for almost 40 years.

Ectodermal dysplasias are inheritable conditions that involve defects in the hair, teeth, nails and glands. Individuals may develop only a few teeth; some develop no teeth. As you know, teeth are "medically necessary" to maintain good nutrition, speech, facial symmetry, and normal growth and development. Some affected individuals go a lifetime without teeth. There are significant medical and social implications associated with this. Children who do not develop normal teeth can suffer from failure to thrive, have speech problems, digestive disorders and many other medical problems. As a result, they have to undergo many costly medical procedures and years of costly speech therapy, all that are unnecessary if they just had teeth!

Many individuals call our office on a daily basis seeking help to get teeth for themselves or their children. Insurance companies regularly deny coverage for teeth even though most states have statutes that require such coverage of congenital defects. Insurance companies routinely deny the claims as "cosmetic." When in the world did simply having teeth become cosmetic in this country? Families are denied coverage over and over again after years of fighting. Teeth are not cosmetic and restoration of congenital defects, including congenital dental/oral defects, should be included in all medical insurance policies. It is time for this injustice to stop.

Three years ago, the NFED embarked on a mission to advocate for federal legislation that would mandate coverage for all medically necessary restorations for ALL individuals affected by a congenital disorder. Led by a strong family advocacy committee, we have worked very hard to get legislation introduced. We found great friends and allies, Senators Tammy Baldwin and Joni Ernst and Representatives Colin Peterson and Denver Riggleman. With their dedicated support, the Ensuring Lasting Smiles Act (H.R. 1379, S.560) (ELSA) was introduced as a bill in the U.S Senate and House on February 26, 2019.

Our family advocacy committee has made numerous visits to Capitol Hill and thousands of calls to legislators to garner support for this bill. We are diligent and tenacious in our efforts, and we will not stop until we are successful because this is the #1 issue which most affects our community financially.

People affected by ectodermal dysplasias are expected to have to pay approximately $150,000 out of pocket just for their dental care during their lives.

The NFED and our partners strongly support ELSA. Please hear our voices; listen to our pleas for equal health care for individuals who are affected by rare congenital disorders. Families are counting on you. We urge you to pass this bill in the 2020 year.

Sincerely,

Mary Fete

Mary Fete, MSN, RN, CCM
Executive Director

Karl Nelsen, PA-C, MS
Board President

Attachment 4. Support Letter from Members of the "Ensuring Lasting Smiles Act" Coalition

Jan. 3, 2020

The Honorable Anna Eshoo	The Honorable Michael Burgess
Chair, Health Subcommittee	Ranking Member, Health Subcommittee
House Committee on Energy & Commerce	House Committee on Energy & Commerce
2125 Rayburn House Office Building	2125 Rayburn House Office Building
Washington, D.C. 20515	Washington, D.C. 20515

Dear Chairwoman Eshoo and Ranking Member Burgess:

The undersigned organizations write to express our support for HR 1379, the Ensuring Lasting Smiles Act (ELSA). We appreciate your leadership in recognizing the importance of this bill by including it as part of the Health Subcommittee's Jan. 8 hearing entitled, "Legislation to Improve Americans' Health Care Coverage and Outcomes."

This legislation – with more than 260 bipartisan cosponsors – will have a direct impact on patients and will eliminate the existing burdens that prevent access to necessary diagnosis and treatment for those with congenital craniofacial anomalies, such as cleft lip and palate, skeletal and maxillofacial abnormalities, facial paralysis, microtia, hypodontia, and craniosynostosis. Specifically, if enacted, ELSA will ensure all group and individual health plans cover medically necessary services, including needed dental procedures such as orthodontic or prosthodontic support, as a result of a congenital anomaly. It would exclude coverage for cosmetic procedures or surgery on normal structures.

The Centers for Disease Control and Prevention (CDC) classifies birth defects as "common, costly, and critical" and reports that one in 33 newborns in the United States suffers from a congenital anomaly. Craniofacial anomalies, for example, can restrict a patient's ability to breathe, eat, and speak in a normal manner. Therefore, highly personalized surgery to repair an anomaly helps the patient grow and function normally. Early intervention by a team of specialists, including plastic surgeons, oral and maxillofacial surgeons, pediatric dentists, orthodontists, dermatologists and speech therapists, is necessary to assess and oversee the patient's treatment and development, sometimes over the course of several years.

Most private health plans provide coverage for the surgical treatment of congenital anomalies and many states require insurers to provide coverage of any health services related to congenital anomalies or birth defects. Despite this, health plans often deny claims and appeals for oral or dental-related procedures – like orthodontia and dental implants – or other procedures, which are often crucial to the overall success of treatment, claiming these services are cosmetic.

Severe dental anomalies are a common symptom of many craniofacial anomaly conditions requiring serious medical treatment that is outside the scope of procedures covered by dental plans. As a result, patients are forced to incur significant out-of-pocket costs on medically necessary reconstructive dental care related to their disorder during their lifetime. When private insurance denies a child's reconstructive surgery, families many times end up turning to Medicaid, SCHIP, or other state-sponsored programs for coverage.

The Ensuring Lasting Smiles Act would address these coverage denials and ensure that all patients with birth defects or anomalies get the treatment they need.

For these reasons, we support the Ensuring Lasting Smiles Act and urge members of your subcommittee to help advance this bill through the House.

Sincerely,

Academy of General Dentistry

American Academy of Neurology

American Academy of Pediatric Dentistry

American Association of Oral and Maxillofacial Surgeons

American Association of Orthodontists

American College of Surgeons

American Dental Association

American Society of Dentist Anesthesiologists

American Society of Plastic Surgeons

Dermatology Nurses' Association

International Pemphigus and Pemphigoid Foundation

March of Dimes

National Foundation for Ectodermal Dysplasias

National Organization for Rare Disorders

Noah’s Hope

Pathways for Rare and Orphan Studies