

SAMPLE LETTER - RICK AND LAURA STEYER

As your constituent, I am asking you to join Senators Tammy Baldwin and Joni Ernst and Representatives David Young and Collin Peterson in co-sponsoring the “Ensuring Lasting Smiles Act (ELSA)”. This legislation will require health plans to cover medically necessary services for individuals affected by congenital anomalies, including oral treatment for people with ectodermal dysplasias.

Ectodermal dysplasias are rare, genetic disorders affecting an estimated 3.5 in 10,000 individuals. People with these conditions lack the ability to properly develop teeth, breast tissue, sweat glands, hair and nails. Their teeth may be missing, completely absent, have defective enamel or be shaped differently. If the teeth are not repaired and/or replaced, these individuals will have chewing, swallowing, digestive, speech and self-esteem issues.

States have existing statutes that mandate medical benefits to “people born with a congenital anomaly and resultant missing/defective body parts”. Yet, insurance companies auto-deny claims for medical treatment when the missing body part is TEETH. ELSA would close this loophole and ensure that health plans cover the complex oral restorative care families affected by ectodermal dysplasias need.

On average, someone born with ectodermal dysplasia spends a significant amount of money on necessary medical and dental care throughout their lifetime.

My Personal Story:

Our son, Dylan, who is now 19 months old, has x-linked hypohydrotic ectodermal dysplasia (XLHED), a rare, genetic, birth disorder. Our family lives in Lake County, Indiana.

Dylan seemed completely healthy at birth. He had no body hair whatsoever; no eyelashes, eyebrows, or hair on his head, but we didn't think much about it. He didn't get any teeth until a little after 12 months. He only got two on the top and they were spaced far apart and conical in shape. As a nurse of 12 years and a mother of three, I knew something was wrong. My pediatrician didn't seem concerned.

I diagnosed him myself through Google. I came across XLHED and up popped pictures of other little boys that looked just like my Dylan. I took him to my pediatric dentist who did X-rays and confirmed Dylan had no other teeth. My dentist had actually treated another patient with XLHED and knew what it was. He referred us to a University Children's hospital where Dylan was officially diagnosed.

Along with only having two teeth, his sweat glands don't function properly, making a fever or even a warm environment very dangerous for him. He has sensitive skin and gets rashes easily. He is also very fair skinned, with thin light scalp hair and no body hair. Dylan also has high blood pressure and thickening of his heart because of the high blood pressure. He has to take medication three times a day. We see 10 different specialists at the children's hospital, plus speech therapy. Dylan already has difficulty speaking and eating a nutritious diet. He has already been admitted in the hospital five times. Luckily, our insurance covers all of this, except the dental care he will need in the future.

Dylan will get dentures around the age of four. He will need replacement sets about every two years as he grows. The plan will then be to have bone grafting, possible jaw reconstruction, and dental implants around the age of 17. The cost of all of this is astronomical >\$150,000, more than any middle class family can afford. Dentures and dental implants are not cosmetic for kids with XLHED. My son needs teeth for his jaw to develop, to eat, chew, speak clearly, and for his self-esteem to fit in with his peers. It is a medical necessity for him. Insurance claims the dental care needed is cosmetic, and many other families of children with XLHED older than my son have spent years getting denied by insurance and fighting appeals.

Please co-sponsor the Ensuring Lasting Smiles Act with Senator Baldwin. Dental care for ectodermal dysplasias is medically necessary. Teeth are not cosmetic.

Thank you for taking the time and listening to my family's needs,
Rick, Laura, and Dylan Steyer

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Supporting you. Supporting each other.

NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS