

# SAMPLE LETTER - JULIE CLAEYS

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, Carver, is now 21 years old and affected by hypohidrotic ectodermal dysplasia. It is a congenital abnormality in which he has no sweat glands and can easily overheat; eczema; sparse hair; and was born without teeth. He has worn dentures since the age of two and has had many sets remade as he grew and his dental needs changed.

He cannot eat and chew well without his dentures. He is bullied if seen without his teeth by other kids. He has stomach aches if he does not chew his food well with his dentures. Because he has no teeth, he did not develop healthy bone along the jaw line.

Carver was fitted for lower implants at the age of 13 (the age when the male lower jaw matures) and is now undergoing upper implants after a bone grafting surgery heals in order to hold the new implants at the age of 21. Implants are by far the best fit and best improvement that give Carver a normal set of teeth that function the closest thing to real teeth, and they promote bone growth!

We estimate we have paid over \$75,000 in dental claims thus far. Our “self-funded Aetna/UPS plan” denies medical and dental coverage for any dental needs. They will only insure teeth one is born with. We have tirelessly submitted years of documentation to help support his needs of proper dental care and prosthetics, yet we are denied every time. His dental needs will never end throughout his lifetime.

We are asking our legislators to pass a law for people born with ectodermal dysplasias to obtain dental care through their MEDICAL INSURANCE PLAN as this is a birth defect, congenital abnormality, similar to cleft lip, and absolutely needed in order to function with a healthy lifestyle. This is NOT COSMETIC as the insurance company describes in their reason for denial.

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,

Julie Claeys

**nfed**

Supporting you. Supporting each other.

NATIONAL FOUNDATION FOR  
ECTODERMAL DYSPLASIAS