

SAMPLE LETTER - BETH POND

Dear (insert name of your legislator),

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:

My brother and two sons were born with x-linked hypohidrotic ectodermal dysplasia. Philip and Nolan were born with four teeth. When they were three years old, they were fit for dentures. Our health insurance denied our claim based on their decision that dentures are cosmetic and are not covered under our insurance policy. After fighting the decision for a year, we won our appeal and insurance paid for their dentures.

As the boys grew older, they started to lose bone in their jaw. After seeing their oral surgeon, it was determined that the only medically necessary treatment was bone grafting to build the bone and dental implants for proper functioning and nutrition. We started this process with Philip in early 2013 and finished in late 2016.

The total cost for this medically necessary treatment was \$120,000. As he went through the process, the doctor would present the treatment plan to our insurer for payment and it would get denied. I would spend many hours appealing the decisions. After several months of fighting it would get approved so the next step in the process could get completed.

This went on for over two years with the end result being insurance paid for \$85,000. Our out-of-pocket cost was \$35,000. If Philip was born with teeth and he lost them in an accident, health insurance would cover the cost of replacing them. Why do health insurance companies not recognize missing and deformed teeth are one of the major pieces with people born with ectodermal dysplasias?

We need your help. 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,

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Supporting you. Supporting each other.

NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS