

SAMPLE LETTER - BECKY ABBOTT

As your constituent, I am asking you to co-sponsor 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:

I am a rare disease advocate & the mother of Aidan Abbott, a child with x-linked hypohidrotic ectodermal dysplasia or XLHED. Our family lives in Washington County. After many years of appointments with specialists at Children’s Hospital of Wisconsin, a dental resident as well as a geneticist diagnosed my son with XLHED. This disease affects Aidan’s skin, hair, nails, sweat glands and teeth. His skin is very sensitive and gets rashes easily. His nails are sensitive and hurt when clipped. His sweat glands don’t function properly so he has a hard time regulating fevers and overheats easily. He was also born without many of his teeth, which affect his quality of living.

When he first started his dental procedures after diagnosis, we were told that since teeth were a medical necessity and this was a congenital abnormality, that his complex dental work should be covered by insurance. We soon discovered that very little is covered, and our insurance will not make an exception to cover further work. Each time we submitted a claim, we have had to appeal several times. Now that Aidan is older, and the majority of his dental work needs to begin, we have been told that they have made their final decision to deny dental work.

While our state does have legislation to include coverage of congenital abnormalities/ anomalies, my husband’s employer, Washington County Sheriff’s Department, has a self- funded/pay policy and refuse to follow the statutes. Many insurance companies and employers also do not feel they have to cover oral health care and treatments due to congenital abnormalities, because it is not specifically mentioned in legislation.

Aidan has had several issues due to his lack of teeth, including speech, swallowing, chewing, eating, and being made fun of by other kids. He has had to go through invasive procedures, just to determine that his issues are due to his lack of teeth. Other families that have had these complex dental issues and absence of teeth have had to pay over \$100,000 for dental work. If teeth are not replaced at an appropriate age, it could lead to further issues including loss of bone and a need for bone grafts and dental implants in the future. Teeth are not just esthetic, they are a medical necessity and important for quality of life.

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,
Becky M. Abbott, MPH



Supporting you. Supporting each other.

NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS