

# SAMPLE LETTER - EXTENDED FAMILY MEMBERS

August 18, 2018

Senator Elizabeth Warren  
317 Hart Senate Office Building  
Washington, DC 20510

Dear Senator Warren,

I am writing to you as a Massachusetts grandmother of two young men born with a rare genetic disorder called hypohidrotic ectodermal dysplasia. My hope and purpose of this letter is to give you an understanding of this congenital anomaly and how S.3369 - Ensuring Lasting Smiles Act (ELSA) can change the lives of my grandchildren and other affected families living in Massachusetts.

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.

So let me tell you how it affects my grandsons, Nolan and Philip. The boys do not have any sweat glands, have very sparse hair and lots of skin problems. Their biggest health issue is that both were born with only four tooth buds which only developed into four baby teeth. There were no adult teeth behind those. They were fitted for dentures at three years old. Insurance refused to pay, saying dentures were cosmetic. They were bullied and made fun of because they looked different. The first thing other children noticed was that they didn't have any teeth. They were not getting the proper nutrition and were underweight and choked on their food. Their insurance company denied on the basis this treatment was cosmetic! My daughter appealed and they overturned the decision. Tufts agreed to pay for the dentures until they were fully grown. As the boys grew, they started losing jaw bone. There was only one treatment plan available to them now that they were older.

At 18, the oral surgeon created a "medically necessary oral health" treatment plan which included implants. This was the only treatment plan to restore proper functioning. The cost of this treatment plan was \$125,000. The oral surgeon submitted the bill and it was denied. My daughter would not accept this decision so she spent months working through the appeals process. Harvard Pilgrim finally approved all but 30K. What does not make sense is they were born with teeth and lost them in an accident, health insurance would cover the cost of replacing them. But my grandsons were born without any teeth and my daughter and son-in law had to take out loans to pay for this medically necessary treatment. It doesn't make any sense and I am asking for your help.

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 will close this loophole and ensure that health plans cover the complex oral restorative care that families affected by ectodermal dysplasia need.

This is a huge issue for my grandsons who live in Hubbardston, Massachusetts. Nolan and Philip's daughters will be carriers so this does not just stop with them. I love my grandchildren and it is heart wrenching to watch them suffer at the hands of insurance companies. It is not right and I hope that you will contact Sen. Baldwin, sign on to ELSA so Mass families can get the coverage for medically necessary repair of congenital anomalies. Teeth are not cosmetic!

I am counting on you to support my family by co-sponsoring S.3369 - Ensuring Lasting Smiles Act (ELSA) .

Thank you,

Lillian Brown  
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Supporting you. Supporting each other.

NATIONAL FOUNDATION FOR  
ECTODERMAL DYSPLASIAS