Your Name, Your Address, City, State, Zip

Your E-mail and Your Phone

Today’s Date

Office of Representative (Name)

U.S. House of Representatives

Washington, DC 20515

(202)-224-3121

Re: Health—Federal Congenital Anomaly Law

Dear Representative (Name),

On July 19, 2017, families affected by ectodermal dysplasias, a congenital anomaly, traveled from 35 states to Capitol Hill to tell our stories. We need your help and support to get a bill drafted, introduced and signed into law. The law will protect our families from health insurance denials for TEETH, when benefits should have been covered and paid.

Ectodermal dysplasia is rare and affects an estimated 3.5 in 10,000 individuals. People born with ectodermal dysplasia lack the ability to properly develop and grow hair, nails, breast tissue, sweat glands, and TEETH. It is the extensive problems with TEETH (no teeth, many absent teeth, defective teeth, and associated maxillary/mandibular bone loss) that we are focused on legislatively.

As a first step to raise awareness for ectodermal dysplasias, Senator Tammy Baldwin of Wisconsin on July 20, introduced Senate Resolution S.Res. 226. Representative Jackie Speier of California introduced the same Resolution in The House, H.Res 464.

We are your constituents and are affected by ectodermal dysplasia. **We ask that you co-sponsor**

**H.Res. 464.** We ask that you show supportfor us and National Ectodermal Dysplasias Awareness Week, designated to raise awareness and understanding of ectodermal dysplasias. We need bipartisan support. The Resolution explains our congenital anomaly and our struggle in getting insurance companies and ERISA and non-ERISA plans across the nation to pay for our necessary medical care and treatment for our TEETH. This Resolution is our first step towarda federal law mandating medical coverage for our medically necessary oral restoration care.

Health insurance is regulated by the states. Most of the 50 states have congenital anomaly laws. Benefits for our TEETH are auto-denied because our congenital anomaly, our medical condition, our affected body part is our TEETH. Claims people go right to the dental exclusion and deny treatment, rather than going straight to the congenital anomaly language where the coverage is.

Many self-funded ERISA and non-ERISA employer-sponsored health benefit plans offer congenital anomaly protections too and all with the same results. Benefits for TEETH are auto-denied. It’s as though TEETH and the bone that holds them in place aren’t body parts.

While dental benefits are routinely excluded under health benefit plans, almost all states have Regulations providing an exception to the dental exclusion for “accidental injury to sound and natural” TEETH. If you’re in a car accident and all of your sound and natural teeth land all over the dashboard, your health insurance plan will pay benefits for treatment. Clearly, the states understand the value and importance of having TEETH. So why are we excluded? We believe that when these State Regulations were written, lawmakers simply had no idea that people like us could actually come into this world without any TEETH or bone to hold them in place. We have been fighting with our health plan providers generation after generation. A federal law will put “TEETH” into existing congenital anomaly laws written by our sovereign states that are failing us. Dental treatments, including dentures and implants, for people with ectodermal dysplasias can cost up to $150,000 in a lifetime, out of reach for many of us.

**(ADD YOUR INDIVIDUAL & UNIQUE STORY/FAMILY STORY HERE)**

We need your help. Senator Baldwin, Rep. Speier, Rep. Khanna, Rep. Peterson, Rep. McGovern, Rep. Schiff, Rep. Costello and others are helping us raise awareness for ectodermal dysplasias. **Please join them and support our families by co-sponsoring H.Res. 464**, our first step to getting the federal law we need. It will mandate health insurance companies and self-insured ERISA and non-ERISA health benefit plans to ensure that:

Coverage from the moment of birth shall consider congenital defects and birth abnormalities as an injury or sickness and shall cover the functional repair or restoration of any body part and **may not exclude any body part,** including the TEETH and bone that holds the teeth, when necessary to achieve normal body functioning, but shall not cover cosmetic surgery performed only to improve appearance.

Sincerely,

\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_\_

YOUR NAME HERE)