

# SAMPLE LETTER - FRIENDS

August 18, 2018

U.S. Representative William Keeting  
2351 Rayburn House Office Building  
Washington, D.C. 20515

Dear Congressman Keeting,

My name is Emilie and I live in Harwich, Massachusetts. As a resident in your district, I am asking you to help two friends who are also Massachusetts residents. They have a rare genetic disorder, which seriously affects their oral health and overall quality of life. H.R.6689-Ensuring Lasting Smiles was introduced by Congressman Peterson this past August that would help my friends get their complex oral restorative care covered under their health insurance plan. Let me explain.

My friends Philip and Nolan were born with a rare genetic disorder called hypohidrotic ectodermal dysplasia. Here is information from the National Foundation for Ectodermal Dysplasias (NFED) website. Please go to [www.nfed.org](http://www.nfed.org) for more detailed information. 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.

My friends were born with only a few teeth. They have worn dentures since they were three years old. They are now in their early twenties and are in a tough situation with getting their medically necessary oral health care needs met. Their insurance company is denying dental implants. Because they do not have teeth, they have been losing bone in their jaw. The only treatment option that would work to restore function is dental implants. Their insurance companies have denied them the treatment even though the oral surgeon has stated it is the only treatment option for their health. It's so unfair that if you have teeth and get into an accident and lose them, insurance will pay to have them replaced but not if you were born with a birth defect that affects your teeth.

Please help my friends by co-sponsoring H.R.6689 - Ensuring Lasting Smiles Act (ELSA). My friend's Congressman McGovern was one of the first to co-sponsor this bill. Will you be next? Please contact Congressman Peterson's office and tell him you want to be a co-sponsor. Please help my friends and people born with ectodermal dysplasias. Teeth are not cosmetic!

Thank you,

Emilie Smith  
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**nfed**

Supporting you. Supporting each other.

NATIONAL FOUNDATION FOR  
ECTODERMAL DYSPLASIAS