

May 8, 2020

Senator _____
address
address

RE: Support for the Ensuring Lasting Smiles Act (ELSA), S. 560

Dear Senator _____:

I am writing to urge you to support the Ensuring Lasting Smiles Act, which was introduced by Senator Tammy Baldwin and Senator Joni Ernest. This bipartisan legislation will have a direct impact on patients and will eliminate the existing burdens that prevent access to necessary treatment. This bill would require all private group and individual health plans to cover medically necessary services resulting from a congenital anomaly or birth defect. It would include inpatient and outpatient procedures, as well as adjunctive dental, orthodontic, or prosthodontic support.

X-linked Hypophosphatemia is a rare metabolic bone disease (1 in 20,000 are affected) caused by a mutation in the gene PHEX. It is X-linked dominant and affects females and males resulting in dental and skeletal abnormalities. Children and adults demonstrate signs and symptoms as XLH affects the entire body across the lifespan. The physical signs and symptoms include, but are not limited to delayed growth and short stature, rickets and osteomalacia, enthesopathy and spinal stenosis, hearing loss and dental complications. Dental alterations and delays in eruption are found in both the deciduous and permanent teeth of XLH patients. The teeth of patients with XLH demonstrate shortened roots, enlarged pulp chambers and inadequate dentin mineralization. Due to these characteristics, bacteria enters the microporosities in the dentin and in the enlarged pulp chamber give rise to painful spontaneous dental abscesses in the absence of caries (cavities) and trauma. Other dental complications can occur due to general alveolar bone loss as the teeth loosen and ultimately are lost. It is common for patients with XLH to lose permanent teeth in early to mid-adulthood.

Patients with XLH require significant dental examinations and procedures throughout life including frequent professional cleanings (every 3 months), root canals, extractions, dental implants and bone grafts. The physical medical complications are equally devastating and many patients are on disability due to the disease impacting their ability to work. Those who do work sometimes need to reduce their hours or have several part-time jobs and dental insurance is either inadequate or nonexistent. This congenital anomaly causes severe oral deficits and interferes with our ability to function in a normal manner. In some cases extensive dental procedures or specialized surgery is needed to correct the anomalies. The procedures are reconstructive in nature and are performed to correct abnormal structures of the body. Despite this many insurance companies consider these services to be cosmetic, and fail to recognize the medial conditions of the patient.

I appreciate your leadership in recognizing the importance of ensuring access to the care and services necessary to improve and restore function due to a congenital anomaly. I am respectfully requesting your support for the Ensuring Lasting Smiles Act, which would require all private group and individual health plans to cover medically necessary services that repair or restore a patient's congenital anomaly.

Thank you again for your support and leadership on this important issue.

Sincerely,