

U.S. Sen. Baldwin: Joins U.S. Sen. Joni Ernst to introduce bipartisan reform to ensure coverage for children born with congenital anomalies or birth defects

Posted on Thursday, Aug 23, 2018

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Contact: press@baldwin.senate.gov, 202-224-6225

WASHINGTON, D.C. – U.S. Senators Tammy Baldwin (D-WI) and Joni Ernst (R-IA) today introduced bipartisan legislation to ensure health insurance coverage for needed treatment and procedures for individuals both with congenital anomalies or birth defects. The *Ensuring Lasting Smiles Act* would close a coverage gap to ensure that health plans cover medically necessary services related to a patient's anomaly or birth defect, including any serious dental and oral-related procedures that are necessary to maintaining health and overall function.

Senator Baldwin worked on this legislation after hearing the story of 13 year-old Aidan Abbott of Slinger, Wisconsin who was born with Ectodermal Dysplasia (ED), a rare congenital disease, and who has needed intense dental and oral care and will need reconstructive surgeries throughout his life, among other services related to ED. Despite having comprehensive health insurance, the Abbotts were denied coverage for Aidan's dental work and forced to pay out of pocket for his treatments. Although most health plans cover care for congenital anomalies, claims are routinely denied or delayed for any oral or dental related procedures due to an individuals' disorder.

"Aidan's story has inspired my work on this issue to guarantee that individuals born

with congenital anomalies have access to the comprehensive health treatments and coverage they need and deserve,” **said Senator Baldwin.** “Despite covering all of his other medical care, his family’s insurance continues to refuse to cover his dental care needs, forcing them to spend thousands of dollars out of their own pockets. That’s why I’m introducing bipartisan legislation to close this loophole and make sure families like Aidan’s can get the health care they need at a price they can afford.”

“The *Ensuring Lasting Smiles Act (ELSA)* will close a loophole that has allowed insurance companies to systematically deny claims for medically necessary treatments for our children and families,” **said Becky Abbott from Slinger, WI.** “We are thankful that Senator Baldwin listened to Aidan’s story and has taken action with Senator Ernst, to ensure families with ectodermal dysplasias and congenital anomalies get the coverage they desperately need.”

Senator Ernst joined Senator Baldwin in introducing this legislation after meeting with the Steele Family of Dallas County, Iowa. At six years old, Allison Steele was diagnosed with Ectodermal Dysplasia (ED), a rare congenital condition that causes the abnormal development of an infant’s skin, hair, nails, teeth, and sweat glands. Having been born with misplaced and missing teeth, even with insurance, the Steele family is looking at paying thousands of dollars in out-of-pocket costs to provide Allison with functional teeth.

“Those born with congenital anomalies or birth defects should be provided with necessary medical services, and the *Ensuring Lasting Smiles Act* will help correct a gap in health insurance coverage and relieve the financial burden for American families. It’s stories like Allison’s that make this legislation so important, ” **said Senator Ernst.**

“Our community is incredibly grateful to our champions Senator Baldwin and Senator Ernst,” **said Mary Fete, executive director of the National Foundation for Ectodermal Dysplasias.** “ELSA is life changing for individuals who are affected by ectodermal dysplasias and other congenital anomalies. It means that they will receive the medically necessary treatment, including oral health care without fighting a long and often losing battle.”

About four percent of children in the U.S. are born with congenital anomalies or birth defects that affect the way they look, develop, or function, often for the rest of their lives. Many born with congenital anomalies suffer from severe oral and facial

defects such as cleft lip or palate, skeletal and maxillofacial deformities, hypodontia (absence of teeth) and enamel hypoplasia. Patients who do not have their craniofacial and other anomalies treated face long-term physical and psychological injuries. Individuals who suffer from ED and other craniofacial anomalies can expect to incur significant out of pocket costs on reconstructive oral and dental procedures related to their disorder during their lifetime.

Most health plans provide coverage for congenital anomalies and many states require insurers to provide coverage of any health services related to congenital anomalies or birth defects. Despite this, health plans systematically and routinely deny or delay claims and appeals for any oral or dental related procedures- like reconstructive surgery for a cleft palate, under the pretense that such service is merely cosmetic or covered under separate dental plans. This is a common practice across the country and leaves families with the burden of how to pay for their child's treatment or procedures that are necessary to restore their ability to function. The *Ensuring Lasting Smiles Act* would address these coverage denials and delays and ensure that children suffering from congenital anomalies or birth defects get the reconstructive treatment they need.

Specifically, the *Ensuring Lasting Smiles Act* would:

- Ensure that all health plans cover medically necessary services, including reconstructive surgeries and oral-related procedures, as a result of congenital anomalies or birth defects;
- Stipulate that such coverage include services and procedures that functionally repair or restore any missing or abnormal body part that is medically necessary to achieve normal body functioning or appearance, and clarifies that this includes adjunctive dental, orthodontic or prosthodontic support; and
- Exclude cosmetic procedures or surgery.

A companion bill was introduced in the House today by Representatives Collin Peterson (D-MN07) and David Young (R-IA03).

The bipartisan legislation is supported by the American Association of Oral and Maxillofacial Surgeons (AAOMS), the American Society of Plastic Surgeons (ASPS), the National Foundation for Ectodermal Dysplasias (NFED), American College of Surgeons, American Dental Association, American Academy of Dermatology Association, American Association of Orthodontists, Children's Hospital of Wisconsin, American Academy of Neurology, Rare and Undiagnosed Network (RUN) and

EveryLife Foundation.

More information on the *Ensuring Lasting Smiles Act* is available [here](#).