

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

Posted on Tuesday, Feb 26, 2019

>> **WisPolitics is now on the State Affairs network. Get custom keyword notifications, bill tracking and all WisPolitics content. [Get the app or access via desktop.](#)**

Contact: press@baldwin.senate.gov

202-224-6225

WASHINGTON, D.C. – U.S. Senators Tammy Baldwin (D-WI), Joni Ernst (R-IA), Sherrod Brown (D-OH) and Lisa Murkowski (R-AK) today reintroduced bipartisan legislation to ensure health insurance coverage for needed treatment and procedures for individuals born 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 14 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-related procedures due to an individuals' disorder.

“Aidan’s story continues to inspire my work on this issue to guarantee that individuals born with congenital anomalies have access to the comprehensive health treatments and coverage they need,” **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, Wisconsin**. “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.”

“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 certain services, including 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 treatment they need and deserve.

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.

Bipartisan companion legislation was introduced in the House by Representatives Collin Peterson (D-MN) and Denver Riggleman (R-VA).

The bipartisan legislation is supported by the Academy of General Dentistry, the American Academy of Dermatology Association, the American Academy of Neurology, the American Academy of Oral and Maxillofacial Pathology, the American Academy of Oral and Maxillofacial Radiology, the American Academy of Pediatric Dentistry, the American Association of Oral and Maxillofacial Surgeons, the American Association of Orthodontists, the American Association of Pediatric Plastic Surgeons, the American Association of Women Dentists, the American College of Surgeons, the American Dental Association, the American Society of Craniofacial Surgeons, the American Society of Dental Anesthesiologists, the American Society of Maxillofacial Surgeons, the American Society of Plastic Surgeons, CCD Smiles, Children's Hospital of Wisconsin, Derma Care Access Network, EveryLife Foundation for Rare Diseases, FACES: The National Craniofacial Association, Foundation for Ichthyosis and Related Skin Types, Inc., Genetic Alliance, International Pemphigus and Pemphigoid Foundation, March of Dimes, National Foundation for Ectodermal Dysplasias, National Organization for Rare Disorders, Pathways for Rare and Orphan Studies, Project Accessible Oral Health, Rare and Undiagnosed Network, SunnyStrong, the APS Type 1 Foundation, the Marfan Foundation, and the Sturge-Weber Foundation.

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

An online version of this release is available [here](#).