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NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS



Ensuring Lasting Smiles Act (HR.1916, S.754)

Please cosponsor and support the bipartisan, bicameral *Ensuring Lasting Smiles Act (ELSA)*, which was reintroduced by Senate leads, Senator Tammy Baldwin (D-WI) and Senator Joni Ernst (R-IA), and House leads, Congresswoman Anna Eshoo (D-CA-18) and Congressman Drew Ferguson (R-GA-3), for the 117th Congress.

In the 116th Congress, this bill gained strong bipartisan support from 53 U.S. Senate cosponsors, 313 U.S. House cosponsors, and passed the House Energy & Commerce Committee by voice vote. ELSA is endorsed by a broad coalition of national health care professional and patient advocacy organizations.

Summary: This bipartisan legislation would require all private group and individual health plans to cover medically necessary items and services that are needed to repair congenital anomalies; stipulates that such coverage includes services & 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 the inclusion of adjunctive dental, orthodontic, or prosthodontic support.

Background: About four percent of children in the U.S. are born with congenital anomalies that affect the way they look, develop, or function. Many born with congenital anomalies suffer from severe oral defects (such as cleft lip or palate, hypodontia, enamel hypoplasia), skeletal defects (such as craniosynostosis), vision defects (such as congenital cataracts or aphakia), hearing defects (such as microtia), or other loss of bodily functions. Individuals who do not receive timely, continuous care for their congenital anomalies face long-term physical and psychological injuries.

Problem: Most group and individual health plans include coverages for congenital anomalies, and all 50 states require health insurers to provide coverage for the treatment of congenital anomalies. Despite this, health plans systematically and routinely deny or delay claims and appeals for treatment of congenital anomalies by wrongfully categorizing certain treatments or body parts as cosmetic or not medically necessary. This is a common practice that leaves families with the burden of paying 100% of the cost for their child's medically necessary treatments, despite maintaining private health plans.

Solution: *The Ensuring Lasting Smiles Act* will ensure that group and individual health plans do not deny or delay medically necessary treatments of congenital anomalies, therefore improving the health of countless Americans.

Contact Information: To cosponsor the Senate bill, please contact Sen. Baldwin's office or Sen. Ernst's office. To cosponsor the House bill, please contact Rep. Eshoo's office or Rep. Ferguson's office.

List of Professional and Patient Organizations Supporting ELSA

(Hyperlinks are active when viewed on computer)

Academy of General Dentistry	Costello Syndrome Family Network
American Academy of Dermatology Association	Dermatology Nurses' Association
American Academy of Facial Plastic and Reconstructive Surgery	Derma Care Access Network
American Academy of Neurology	EveryLife Foundation for Rare Diseases
American Academy of Ophthalmology	FACES: The National Craniofacial Association
American Academy of Oral and Maxillofacial Pathology	Foundation for Ichthyosis and Related Skin Types, Inc. (FIRST)
American Academy of Oral and Maxillofacial Radiology	Genetic Alliance
American Academy of Pediatric Dentistry	International Pemphigus and Pemphigoid Foundation
American Association of Oral and Maxillofacial Surgeons	Lupus and Allied Diseases Association
American Association for Pediatric Ophthalmology and Strabismus	Lymphedema Advocacy Group
American Association of Orthodontists	M-CM Network
American Association of Women Dentists	March of Dimes
American Behcet's Disease Association	Moebius Syndrome Foundation
American College of Prosthodontists	National Foundation for Ectodermal Dysplasias
American College of Surgeons	National Organization for Rare Disorders
American Dental Association	Noah's Hope – Hope4Bridget
American Prosthodontic Society	Operation Smile
American Society for Dermatologic Surgery Association	Pathways for Rare and Orphan Studies
American Society of Dentist Anesthesiologists	Project Accessible Oral Health
American Society of Maxillofacial Surgeons	Rare & Undiagnosed Network
American Society of Plastic Surgeons	rareLife Solutions
American Student Dental Association	Soft Bones: The US Hypophosphatasia Foundation
Barth Syndrome Foundation	SunnyStrong
Bridge the Gap – SYNGAP Education and Research Foundation	The APS Type 1 Foundation Inc.
CCD Smiles	The Marfan Foundation
Children's Hospital of Wisconsin	The XLH Network, Inc.
Colorado Rare	The Sturge-Weber Foundation
	Usher 1F Collaborative
	Virginia Council of Nurse Practitioners