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NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS

The Ensuring Lasting Smiles Act – (H.R.1379, S.560)

The Ensuring Lasting Smiles Act (H.R.1379, S.560) has won the support of patients, families, provider organizations, and members of Congress on both sides of the aisle.

SUMMARY: This bipartisan legislation would require all private group and individual health plans (including plans regulated by ERISA) to cover medically necessary services as a result of congenital anomalies or birth defects; stipulate that such coverage includes 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 clarify the inclusion of adjunctive dental, orthodontic or prosthodontic support. The bill excludes coverage for cosmetic surgery to reshape normal structures of the body to improve appearance or self-esteem. ELSA would address delays and denials in coverage and ensure that patients suffering from congenital anomalies receive the treatment they need – and deserve – in a timely manner.

BACKGROUND: 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 anomalies, facial paralysis, microtia, hypodontia (absence of teeth), enamel hypoplasia, and craniosynostosis. On average, children with congenital or developmental anomalies can expect anywhere from three to five surgical procedures before normalcy and function are achieved. Patients who do not have their craniofacial and other anomalies treated face long-term physical and psychological injuries. For example, severe dental anomalies that require surgery and other intensive care are a common symptom of Ectodermal Dysplasias, a rare congenital disease. Individuals who suffer from Ectodermal Dysplasias 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.

PROBLEM: Most private health plans provide coverage for congenital anomalies and all states require insurers to provide coverage of health services and treatments 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. When private insurance denies a patient's reconstructive surgery, families many times end up turning to Medicaid, SCHIP, or other state-sponsored programs for coverage.

SOLUTION: This bill seeks to ensure health plans do not bypass necessary coverages—for which families are paying in premiums, deductibles, and copays—by using loopholes or unintended coverage gaps. Furthermore, ensuring that patients can access the right care at the right time could generate future savings for insurers and families while also fostering better health outcomes. **All 50 states already mandate coverage of medically-necessary treatments of congenital anomalies.** 18 states further mandate specific coverages for various craniofacial congenital anomalies. **Timely care of underlying congenital anomalies drastically reduces or eliminates secondary care and its associated costs; therefore, this bill will generate cost savings to both insurers and patients. Delays in proper care, including dental care, can result in poor outcomes and more expensive care later on.** For example, when insurers decline to cover dental braces when required for craniofacial anomaly treatment, a family may delay

orthodontic treatment while grappling with the denial. Delayed orthodontics will consequently delay required maxillary expansion and surgery, increasing the likelihood of poor outcomes, such as graft failure and failure to maintain adult dentition on the cleft site. Insufficient access to comprehensive, timely orthodontic cleft care unduly compromises a patient's ability to achieve proper eating, sleeping, respiratory, speech and social functionality.

The Ensuring Lasting Smiles Act also has the potential to generate savings due to fewer patients switching from private to public health plans and all states already mandating coverage. Specifically, states would save money on the families who, but for a mandate improving their access to private coverage, would have relied on public insurance to attain access to care. The existence of similar coverage mandates in all states will allay the overall costs of implementing a federal mandate.

BOTTOM LINE: The Ensuring Lasting Smiles Act (H.R.1379, S.560) would provide long overdue consistency in protecting patients nationwide, while also generating cost savings.

SUPPORT: The Ensuring Lasting Smiles Act (S.560/H.R.1379) is supported by more than 50 organizations, including 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 (ACS), American Dental Association (ADA), American Academy of Dermatology Association (AAD), American Association of Orthodontists (AAO), American Academy of Neurology (AAN), March of Dimes, Rare and Undiagnosed Network (RUN), EveryLife Foundation, National Organization for Rare Disorders (NORD), and CCD Smiles.

To co-sponsor S.560 please contact:

Senator Baldwin or Senator Ernst

To co-sponsor H.R.1379 please contact:

Congressman Peterson or Congressman Riggleman