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NATIONAL FOUNDATION FOR  
ECTODERMAL DYSPLASIAS

## **WHAT IS THE ENSURING LASTING SMILES ACT (ELSA)?**

(H.R.6689/S.3369 – These bill numbers will change once ELSA is re-introduced in the 116<sup>th</sup> Congress.)

### **Summary of the Bill**

The Ensuring Lasting Smiles Act would require all group and individual health plans to cover medically necessary services as a result of congenital abnormalities. It would also 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, including teeth. The bill excludes coverage for cosmetic surgery to reshape normal structures of the body to improve appearance or self-esteem.

### **Background**

According to the Centers for Disease Control and Prevention (CDC) – which characterizes birth defects as “common, costly, and critical” – one in 33 babies in the United States is born with a congenital anomaly. Of the 120,000 children born annually with birth defects, approximately 40,000 require reconstructive surgery.

Craniofacial anomalies can restrict a child’s ability to breathe, eat, and speak in a normal manner. Therefore, surgery to repair an anomaly – which is highly individualized – is intended to help a child obtain the ability to function and grow normally.

Examples of these deformities include cleft lip; cleft palate; skin lesions; vascular anomalies; malformations of the ear, hand, or foot; and other more profound craniofacial deformities. Although medical professionals and surgeons are able to correct many of these problems, some insurance companies deny access to care by labeling the procedures “cosmetic” or “non-functional” in nature.

### **The Solution**

On average, children with congenital deformities or developmental anomalies can expect anywhere from three to five surgical procedures and many medically necessary treatments before normalcy and function are achieved.

Although carriers may provide coverage for the initial procedures, they may resist coverage of the later stage procedures, claiming they are cosmetic and not medically necessary. Denial or delay of these procedures – which by definition are reconstructive – could lead to long-term physical and psychological injuries. The Ensuring Lasting Smiles Act would address delays and denials in coverage, and ensure that children suffering from birth defects and anomalies get the treatment they need – and deserve – in a timely manner.

Sen. Tammy Baldwin (D-WI) worked on this legislation after hearing the story of 13-year-old Aidan Abbott of Slinger, Wisconsin who was born with ectodermal dysplasia and who has needed intense dental and oral care and will need reconstructive surgeries throughout his life, among other services related to ectodermal dysplasia. 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.



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## Cost

To protect against increased insurance premiums, the legislation clarifies that coverage may be subject to limits, such as pre-authorization or pre-certification, as long as coverage limits are no more restrictive than for any other injury or sickness.

In addition, when similar, but broader scope, legislation was previously considered by Congress, the Congressional Budget Office (CBO) let the bill sponsors know that the legislation would not exceed the threshold established under the Unfunded Mandate Reform Act (UMRA) and that it would have a negligible effect on federal tax revenues.

## What We Are Asking Congress

Be an original cosponsor of the Ensuring Lasting Smiles Act to ensure children have adequate insurance coverage to treat congenital defects or birth abnormalities. If your senator or representative wants to co-sponsor ELSA, share with them this information:

- To cosponsor H.R.6689, please contact [Tamir.Elnabarawy@mail.house.gov](mailto:Tamir.Elnabarawy@mail.house.gov) (Rep. Peterson).
- To cosponsor S.3369, please contact [Kathleen\\_Laird@baldwin.senate.gov](mailto:Kathleen_Laird@baldwin.senate.gov) (Sen. Baldwin) or [Hyder\\_Chowdry@ernst.senate.gov](mailto:Hyder_Chowdry@ernst.senate.gov) (Sen. Ernst).

## Organizations Supporting ELSA

- National Foundation for Ectodermal Dysplasias
- American Academy of Dermatology Associates
- American Academy of Neurology
- American Association of Oral and Maxillofacial Surgeons
- American Association of Orthodontists
- American College of Surgeons
- American Dental Association
- American Society of Plastic Surgeons
- Children's Hospital of Wisconsin
- EveryLife Foundation for Rare Diseases
- Rare & Undiagnosed Network

Learn more at [www.nfed.org](http://www.nfed.org).