



Families affected by ectodermal dysplasias shared their stories with Congress at the National Foundation for Ectodermal Dysplasias Advocacy Day on Capitol Hill in July.

WE MUST DO THIS TOGETHER!

How to Respond to Legislators' Questions

Thank you for advocating for the Ensuring Lasting Smiles Act (ELSA)

(L = Legislator / F = NFED Family member)

(L) Insurance is regulated by the states, why aren't you contacting your state representatives?

(F) The states have failed our families. Most, if not all, of the 50 states have issued state statutes that call for the coverage of repair of congenital anomalies. However, those are either not enforced or cannot be enforced due to federally regulated plan status.

(L) This is a state's rights issue, and power should be left up to the states to regulate insurance. Why should I support a federal mandate that would take power away from the states?

(F) While we appreciate your stance on state's rights issues, many plans are self-funded and federally regulated. With the rise in popularity of self-funded plans, more plans will continue to be federally regulated. It is in direct conflict to say states should have regulation over policies and then allow employers to choose self-funded plans that are federally regulated.

(L) We don't support disease specific legislation. Why support legislation that only helps people with ectodermal dysplasias?

(F) This legislation is not disease specific. It is actually broad in scope and will provide coverage for the repair of any congenital anomaly, not just ectodermal dysplasias. While it does specify teeth and oral treatments, this will help any individual born with a congenital anomaly that requires medically-necessary treatments to repair their congenital anomaly.

nfed

Supporting you. Supporting each other.

NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS

(L) How can I help your family?

(F) You can support and co-sponsor the Ensuring Lasting Smiles Act with Senator Baldwin, Senator Ernst, Congressman Peterson, & Congressman Rigglesman. We need your help to ensure that all families struggling with insurance coverage, receive the medically-necessary treatments they desperately need.

(L) Won't the burden of cost be too high and wont premiums go up, due to this new federal mandate?

(F) 1. Families will still need to pay their premiums and deductibles before they receive any type of coverage for repair of congenital anomalies. (Some of the ACA mandates provide coverage for preventative care, etc. without the deductible being met. We are not asking for this). The repair of congenital anomalies will be treated as any other claim in our policy and will have to adhere to co-pays, premiums, and deductibles, depending on the policy.

2. We are talking about a small portion of the population who are born with congenital anomalies. The CDC has a statistic that 4% of Americans are born with congenital anomalies. Keep in mind, though, that a portion of that 4% already receive coverage for the repair of their anomalies. Therefore, there will very likely be no impact to premiums.

3. Children who don't have their congenital anomalies repaired often go through unnecessary medical procedures that cost insurance companies.

Example: Due to Aidan's lack of teeth, his doctor had him get an endoscopy, swallowing tests, and he had to go through over three years of speech therapy. These were all paid for by insurance or our local Birth to 3 program through our county. Not to mention the stress that it causes children to have to be anesthetized and hospitalized for these procedures. If the original abnormality is addressed and corrected it would cut down on costs for unnecessary procedures and services.

4. These are already covered services/treatments in most policies. Families are already paying for congenital anomaly coverage in their existing premiums and deductibles. We are asking for these policies to be enforced by closing the loophole so insurance companies can no longer automatically deny these claims based on arbitrary decisions that deem these treatments to be "cosmetic" or not related to health care.

(L) What is the cost of the Bill?

(F) In a previous congress, the Congressional Budget Office took an unofficial look at the Children's Access to Reconstructive Education and Surgery (CARES) Act, which proposed to provide similar coverage for a larger patient population. CBO told its sponsors that the cost would not exceed the Unfunded Mandates Reform Act (UMRA) threshold and it would have a negligible effect on federal tax revenues. In addition, this bill is not seeking federal money for treatments, or portions of treatments, that go uncovered by health insurance.

(L) I am not on a committee that ELSA is referred to.

(F) While we understand that you are not assigned to a committee that this legislation is referred to, you can still co-sponsor this legislation. We ask that you support our families and co-sponsor the Ensuring Lasting Smiles Act.

(L) What is the Ensuring Lasting Smiles Act & what does it cover?

(F) 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.

#EnsuringLastingSmilesAct
#TeethAreNotCosmetic

nfed

Supporting you. Supporting each other.

NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS