ELSA
ENSURING LASTING SMILES ACT

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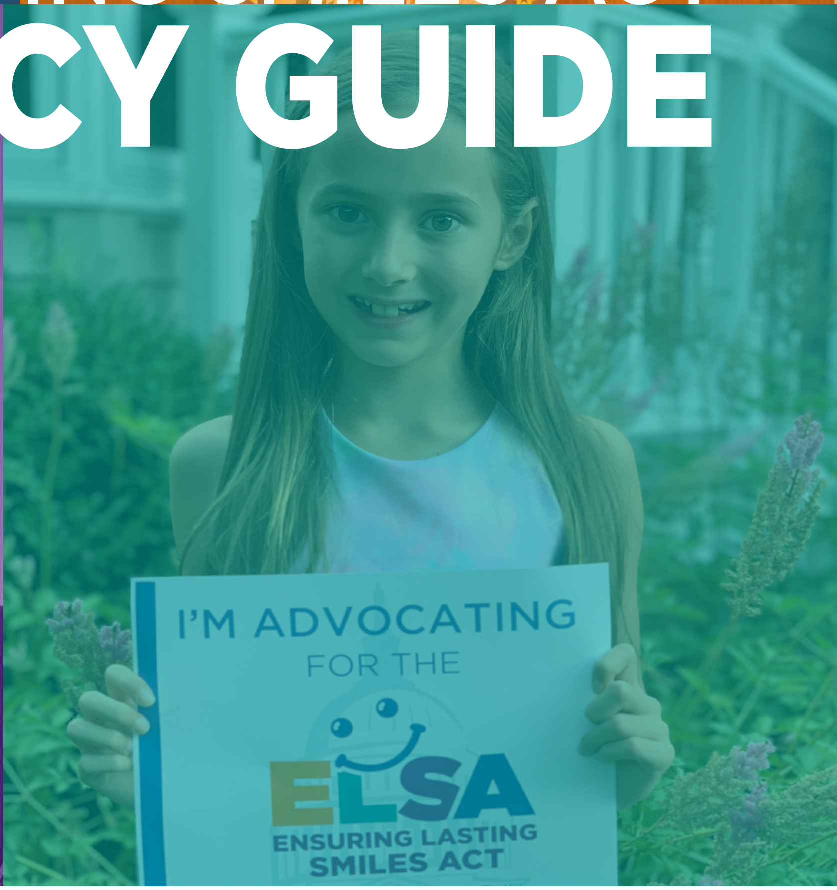
ADVOCACY GUIDE



Your voice can be the difference.

nfed
NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS

What is the Issue?

About 4% 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), 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.

Insurance Loophole Denies Treatment

Health plans systematically and routinely deny or delay claims and appeals for treatment of many congenital anomalies by wrongfully categorizing certain treatments or body parts as cosmetic or not medically necessary.

This common practice leaves families with the burden of paying 100% of the cost for their child's medically necessary treatments, despite maintaining private health plans.

On average, someone born with ectodermal dysplasia spends a significant amount of money on necessary medical and dental care throughout their lifetime. We've seen families sell their cars, remortgage their homes, and forego a college education to afford medically necessary dental care. **Far more families simply go without care because they can't afford it.**

Individuals who lose their teeth due to an accident receive dental benefits under the existing statutes. Yet, those who are missing teeth due to ectodermal dysplasias do not.

ELSA would change this.

Why This Matters Now

This legislation would close an insurance coverage loophole for people born with congenital anomalies who need complex oral restorative care.

ELSA would ensure that individuals and families have coverage for all medically necessary services and procedures related to congenital anomalies that primarily impacts the appearance or function of the eyes, ears, teeth, mouth, or jaw, including but not limited to the many types of ectodermal dysplasias.

ELSA would require a group health plan and a health insurance issuer offering group or individual health insurance coverage, to provide coverage for outpatient and inpatient items and services related to the diagnosis and treatment of a congenital anomaly or birth defect, that primarily impacts the appearance or function of the eyes, ears, teeth, mouth, or jaw. This federal, bipartisan, and bicameral legislation will guarantee the payment of health insurance benefits for necessary medical care and treatment due to congenital anomalies.

ELSA's passing would mean families affected by ectodermal dysplasias and other congenital anomalies could receive the care and procedures they need—and deserve—to gain normal body functions.

The National Foundation for Ectodermal Dysplasias (NFED) along with 70+ ELSA supporting organizations have made it a priority to get the Ensuring Lasting Smiles Act (ELSA) passed.

To learn more about how NFED is supporting this important legislation, visit:

https://nfed.org/get-involved/advocate/

What is Needed to Get ELSA Passed Into Law?

ELSA was reintroduced in the U.S. Senate (S.1677) and U.S. House of Representatives (H.R.3277) on May 8, 2025.

It has gained tremendous bipartisan support since 2018, but it will need to pass both chambers of Congress and be signed into law by the President before the 119th Congress ends in December 2026.

This process starts with you!

Please ask your U.S. Senators and U.S. Representative to support and become a cosponsor of ELSA.

ELSA
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SENATE
Members: 100

HOUSE
Members: 435

Cosponsor number push ELSA towards committee action and then a vote.

> **"With ELSA...there wont be the loophole anymore for insurance to deny us."**
>
> **- Alex and Alexa, advocates from Hawaii**


THIS
ENTRANCE
CLOSED

How Can You Participate in Advocacy for ELSA?

Reach Out to Congress: Head to nfed.org/elsa to quickly send messages urging your U.S. Senators and Representatives to cosponsor ELSA. You can also schedule a meeting with your federal legislators. We can walk you through the steps on how to prepare for your meeting.

Share Your Story: If ectodermal dysplasias or another congenital condition has touched your life, share your personal journey. Your story helps lawmakers understand why ELSA is essential.

Spread the Word Online: Post using the graphics in this toolkit to raise awareness. Be sure to tag your legislators and use hashtags like #PassELSA and #EnsuringLastingSmiles.

Host a Local Event: Plan a community event, a virtual info session, or even walk to bring people together and build support.

Show Your Support Publicly: Hang posters, place signs, or display flyers at your school, workplace, or favorite local businesses to spark conversation.

Engage Community Leaders: Ask your school board, city council, or civic organizations to issue statements of support or pass resolutions backing ELSA.

Invite Others to Join: Encourage family, friends, neighbors, and coworkers to take part — whether by posting online, attending an event, or contacting lawmakers.

Work with the Media: Pitch stories to local journalists and news outlets about ELSA and the families it will benefit.

Use Your Talents: Everyone has something to contribute. Whether you're an educator, artist, health professional, or community organizer, your skills can make a difference.

Find more advocacy resources at
https://nfed.org/get-involved/advocate/advocacy-resources/

Need Guidance? We're here to support your advocacy.

Reach out any time at info@nfed.org.

Join Our Community!

The ELSA Advocates Facebook Group is a great way to connect with fellow advocates, ask questions and share successes or challenges.

NFED staff moderate the group and share advocacy updates.

Join Here

> **“It’s not only incredibly important to me and my family, it’s also a greatly affecting component of other families’ lives across the entire country.”**
>
> **- Emily, advocate from Alaska**

Let Everyone Know You Are Advocating for ELSA!

Whether you are participating in Advocacy Day on Capitol Hill or contacting your legislators with our easy-to-use webtool, share your efforts on social media.

Download and print our “I’m Advocating for ELSA” sign, take a photo with it and share on social media.

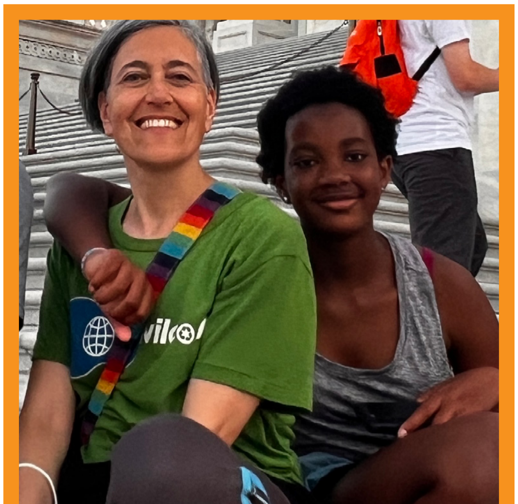
Be sure to use the hashtags:

#EnsuringLastingSmiles
#NFEDOnTheHill
#PassELSA

And ask them to join us!

We’ve also created a sharable advocacy card for advocates to give to anyone who would like to join our advocacy efforts.

The card includes a QR code to our easy-to-use webtool, where supporters can advocate for ELSA directly with their legislators in a matter of minutes.



I’M ADVOCATING

FOR THE

ELSA

ENSURING LASTING SMILES ACT

#EnsuringLastingSmiles #NFEDOnTheHill

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