

Ensuring Lasting Smiles Act Reintroduced to 119th U.S. Congress. [Take Action Now.](#) >
[\(https://nfed.org/get-involved/advocate/ways-to-advocate/#/\)](https://nfed.org/get-involved/advocate/ways-to-advocate/#/)



Together, we **enrich** the lives of people affected by ectodermal dysplasias, creating a brighter future for all those impacted.

DONATE TO LIGHT THE WAY FOR RESEARCH

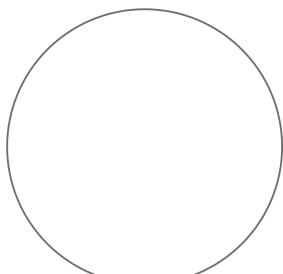
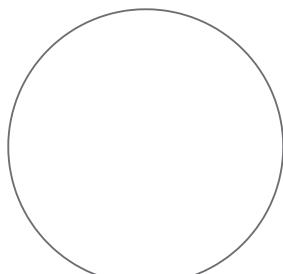
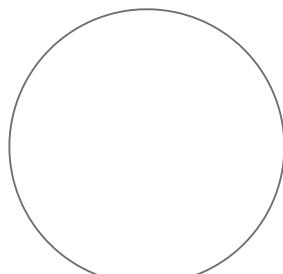
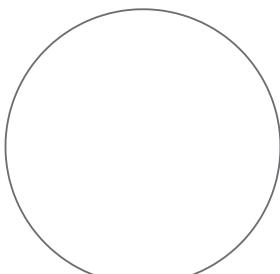
WHAT ARE ECTODERMAL DYSPLASIAS?



The ectodermal dysplasias are inherited disorders that involve defects in the hair, nails, sweat glands and teeth. When a person has at least two types of abnormal ectodermal features—for example, malformed teeth and extremely sparse hair—the individual is identified as being affected by ectodermal dysplasia.

[LEARN MORE \(HTTPS://NFED.ORG/ABOUT-US/\)](https://nfed.org/about-us/)

WHAT'S HAPPENING AT NFED ([HTTPS://NFED.ORG/BLOG/](https://nfed.org/blog/))



(<https://nfed.org/blog/fc25-wrap-up/>)

JULY 22, 2025

Taking Big Steps Forward: How a Mom and Daughter

2025 NFED Family Held Their Own Impromptu Day on the Hill

Conference (<https://nfed.org/blog/fc25-wrap-up/>)

(<https://nfed.org/blog/tara-and-keira/>)

JUNE 10, 2025

How a Mom and Daughter

JUNE 5, 2025 Kristin Matus-Kelso Joins Aspen Group to Promote Free Dental Care

Day on the Hill (<https://nfed.org/blog/tara-and-keira/>)

(<https://nfed.org/blog/kristin-matus-kelso/>)

JUNE 5, 2025

Kristin Matus-Kelso Joins

Aspen Group to Promote Free Dental Care (<https://nfed.org/blog/kristin-matus-kelso/>)

(<https://nfed.org/blog/smile-bridge/>)

JUNE 4, 2025

NFED Partners with

Aspen Group to Promote Free Dental Care (<https://nfed.org/blog/smile-bridge/>)

WE'RE HERE TO LISTEN AND PROVIDE SUPPORT



Browse Our Resource Library (<https://nfed.org/learn/library/>)



Find a Supportive Community (<https://nfed.org/get-involved/connect-our-community/>)



Get Help From NFED Staff (<https://nfed.org/about-us/contact-us/>)

THE IMPACT OF RESEARCH

\$3.6M

Invested in Research

118

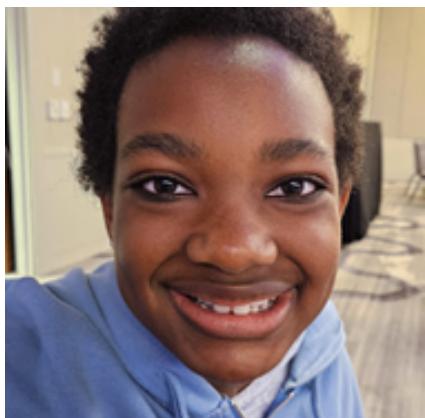
Research Studies and Trials

1,000+

Participants from NFED Families

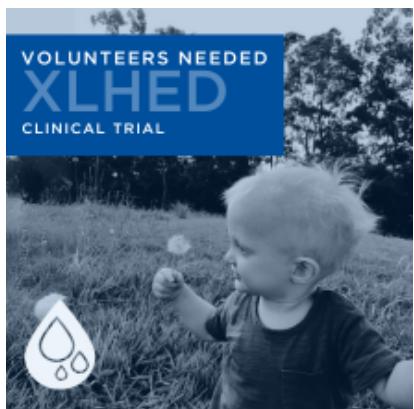
GET INVOLVED IN RESEARCH ([HTTPS://NFED.ORG/RESEARCH/](https://nfed.org/research/))

OUR STORY [\(HTTPS://N OF-HOPE/](https://nfed.org/shareyourstory/)



[\(https://nfed.org/thrive/
meet-our-
families/shareyourstory/\)](https://nfed.org/thrive/meet-our-families/shareyourstory/)

**SHARE YOUR
STORY ›**



Groundbreaking Treatment for XLHED in Development

EspeRare and Pierre Fabre are conducting a clinical trial to test the first potential treatment before birth for x-linked hypohidrotic ectodermal dysplasia (XLHED). The Edelife Clinical trial has sites in six different countries.

Early results showed that six boys who received the prenatal treatment sweat normally and have other improved symptoms. The trial is seeking up to 20 participants. Do you qualify?



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UPCOMING EVENTS >([HTTPS://NFED.ORG/GET-INVOLVED/ATTEND-EVENT/](https://nfed.org/get-involved/attend-event/))

SEP 20, 2025

Nikko for NFED Raffle and BBQ

(<https://nfed.org/events/nikko-for-nfed/>)