



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

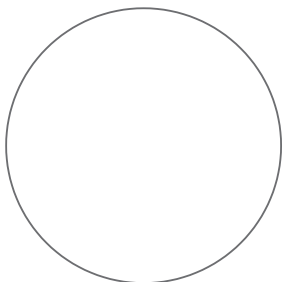
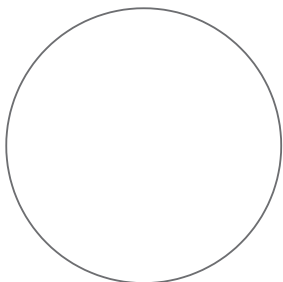
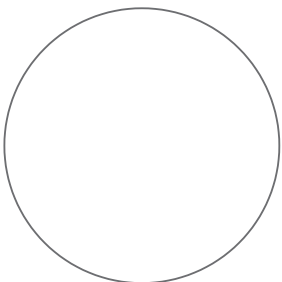
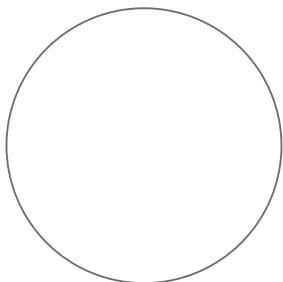


WHAT ARE ECTODERMAL DYSPLASIAS?

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/)



[\(https://nfed.org/blog/fc25-wrap-up/\)](https://nfed.org/blog/fc25-wrap-up/)
JULY 22, 2025
Taking Big Steps Forward: How a Mom and Daughter Held Their Own Impromptu Conference
[\(https://nfed.org/blog/fc25-wrap-up/\)](https://nfed.org/blog/fc25-wrap-up/)

[\(https://nfed.org/blog/tara-and-keira/\)](https://nfed.org/blog/tara-and-keira/)
JUNE 10, 2025
How a Mom and Daughter Held Their Own Impromptu Day on the Hill
[\(https://nfed.org/blog/tara-and-keira/\)](https://nfed.org/blog/tara-and-keira/)

[\(https://nfed.org/blog/kristin-matus-kelso/\)](https://nfed.org/blog/kristin-matus-kelso/)
JUNE 5, 2025
Kristin Matus-Kelso Joins NFED Staff
[\(https://nfed.org/blog/kristin-matus-kelso/\)](https://nfed.org/blog/kristin-matus-kelso/)

[\(https://nfed.org/blog/smile-bridge/\)](https://nfed.org/blog/smile-bridge/)
JUNE 4, 2025
NFED Partners with Aspen Group to Provide Free Dental Care
[\(https://nfed.org/blog/smile-bridge/\)](https://nfed.org/blog/smile-bridge/)

WE'RE HERE
TO LISTEN
AND
PROVIDE
SUPPORT



Browse Our Resource Library
[\(https://nfed.org/learn/library/\)](https://nfed.org/learn/library/)



Find a Supportive Community
[\(https://nfed.org/get-involved/connect-our-community/\)](https://nfed.org/get-involved/connect-our-community/)



Get Help From NFED Staff
[\(https://nfed.org/about-us/contact-us/\)](https://nfed.org/about-us/contact-us/)

THE IMPACT OF RESEARCH

\$3.6M

Invested in Research

118

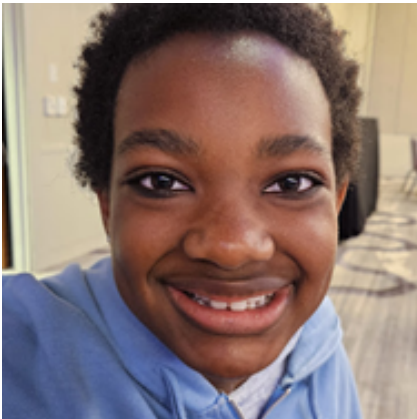
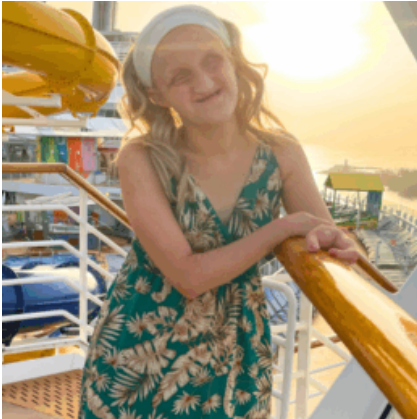
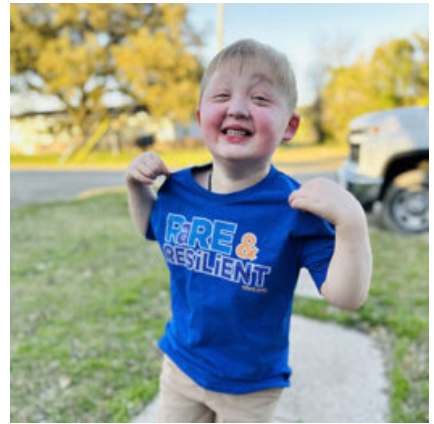
Research Studies and Trials

1,000+

Participants from NFED Families

GET INVOLVED IN RESEARCH [\(https://nfed.org/research/\)](https://nfed.org/research/)

OUR STORY ([HTTPS://NFED.ORG/THRIVE/ MEET-OUR-FAMILIES/SHAREYOURSTORY/](https://nfed.org/thrive/meet-our-families/shareyourstory/))



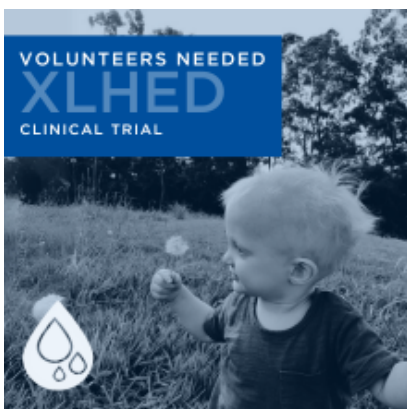
([https://nfed.org/thrive/
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**SHARE YOUR
STORY ›**

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?



LEARN MORE ([HTTPS://NFED.ORG/RESEARCH/PARTICIPATE-RESEARCH/EDELIFE-CLINICAL-TRIAL/](https://nfed.org/research/participate-research/edelife-clinical-trial/))



(<https://nfed.org/join-us/>)



(<https://nfed.org/donate/>)

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/>)