



IN PARTNERSHIP WITH



Supporting you. Supporting each other.

NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS



## WHO WE SERVE

We serve individuals affected by ectodermal dysplasias and their families around the world.



## OUR VISION

The NFED will be known for providing comprehensive services with loving care to individuals affected by ectodermal dysplasias and their families; for helping individuals and families benefit from early diagnosis and care, and for spearheading research that ultimately develops a cure.



## OUR MISSION

To empower and connect individuals touched by ectodermal dysplasias through education, support and research.

How skin conditions **IMPACT** patients



The ectodermal dysplasias are a group of 50+ heritable conditions which affect the skin, hair, teeth, nails and sweat glands. Each type is based on the combination of symptoms experienced. Symptoms can range from mild to severe. The complexity and rarity of the conditions can make diagnosis and access to care difficult for patients.

# OUR STORY

In 1981, Mary K. Richter led 12 families affected by ectodermal dysplasias and established the NFED. Today, the NFED is the worldwide expert on ectodermal dysplasias and the only advocacy organization in the United States dedicated to those living with these disorders.



## HOW WE MAKE AN IMPACT

The NFED offers families extensive, accurate information on their type of ectodermal dysplasia. We offer comprehensive services to meet their many needs. These resources improve their chances of diagnosis and proper treatment.

Bringing families together - online or in person - continues to be what we do best. It empowers families and helps them feel they are not alone.


The NFED has been the driving force behind ectodermal dysplasias research for 30+ years. We have invested \$3.6 million in research and have the first potential treatment for XLHED now in clinical trial. Early results shows that it restores sweat gland function and other XLHED symptoms.


In the U.S., we are passionately leading advocacy efforts for a federal bill called the Ensuring Lasting Smiles Act (ELSA) to be passed in Congress. It would guarantee the payment of health insurance benefits for necessary medical care and treatment due to congenital anomalies.


## AT A GLANCE HOW WE PROVIDE SUPPORT

- Personalized Support
- Educational Materials
- Webinars
- Family Conferences
- Family Liaisons
- Dental Treatment Centers
- Treatment Assistance Program
- Insurance Assistance Program
- Ectodermal Dysplasias International Registry
- Research Program - Dental Implant Program

## GET SOCIAL WITH US

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 @nfed\_org

## SCAN TO LEARN MORE ABOUT NFED



SCAN ME

+1 618 566 2020

6 Executive Dr., Ste. 2  
Fairview Heights, IL  
62208-1360

info@nfed.org  
www.nfed.org