WHAT CAUSES ECTODERMAL DYSPLASIAS?

All ectodermal dysplasias are genetic disorders. This means that they can be inherited or passed on at birth to children whose relatives have had an ectodermal dysplasia. However, it is possible for a child to be the first person in his or her family to be affected by an ectodermal dysplasia. In that case, the condition likely has been caused by a change in the DNA or a genetic mutation.

HOW ARE ECTODERMAL DYSPLASIAS DIAGNOSED?

In some cases, an ectodermal dysplasia is apparent at birth. In other cases, a parent or doctor may only begin to suspect that a problem exists when teeth fail to develop normally. The ectodermal dysplasias are diagnosed by the pattern of what part of the body is affected and how it has developed and functions.

Specific genetic tests to diagnose ectodermal dysplasias are available for only a limited number of ectodermal dysplasias.

ARE THERE CURES FOR ECTODERMAL DYSPLASIAS?

Unfortunately, there are no cures for ectodermal dysplasias, but treatments are available to address the symptoms. Research is ongoing to learn more about how different genes cause ectodermal dysplasias, what may be done to prevent the disorders, and how to better treat individuals who are affected.

ABOUT US

The National Foundation for Ectodermal Dysplasias (NFED), a 501(c)(3) organization, is the worldwide expert on ectodermal dysplasias and the only advocacy organization in the United States dedicated to those living with this condition, which most commonly affects the hair, teeth, nails, sweat glands, and skin.

The NFED strives to empower and connect people through education and lifelong support. We also encourage and support research that improves the health and quality of life of those affected by ectodermal dysplasias and, ultimately, seeks to find cures.

GET INVOLVED

The NFED invites you to join our efforts to help build a strong community of people living with ectodermal dysplasias.

To find out how you can get involved, please call 1-618-566-2020 or visit www.nfed.org.

NORD National Organization for Rare Disorders

PUTTING PATIENTS FIRST National Health Council MEMBER

nfed Supporting you. Supporting each other. NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS

Contact us at NFED.org, info@nfed.org, or 1-618-566-2020.

Supporting You.
Supporting Each Other.

nfed

Supporting you. Supporting each other.

NATIONAL FOUNDATION FOR
ECTODERMAL DYSPLASIAS

ABOUT ECTODERMAL DYSPLASIAS

Ectodermal dysplasias are a diverse group of genetic disorders. In fact, more than 180 different types of ectodermal dysplasias exist. Yet most types share some common features, with symptoms ranging from mild to severe.

COMMON FEATURES OF ECTODERMAL DYSPLASIAS:

1. Hair may be missing, sparse, or very light in color.
2. Teeth may be missing, pointed, or widely spaced.
3. Nails may be thick or thin, abnormally shaped, or ridged.
4. Sweat glands may not work properly or may not have developed at all, leaving people unable to perspire and at risk for overheating.
5. Skin may be thin; dry; and prone to rash, infection, and sunburn.

ABOUT THE NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIAS (NFED)

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.

Our mission is to empower and connect people touched by ectodermal dysplasias through education, support, and research.

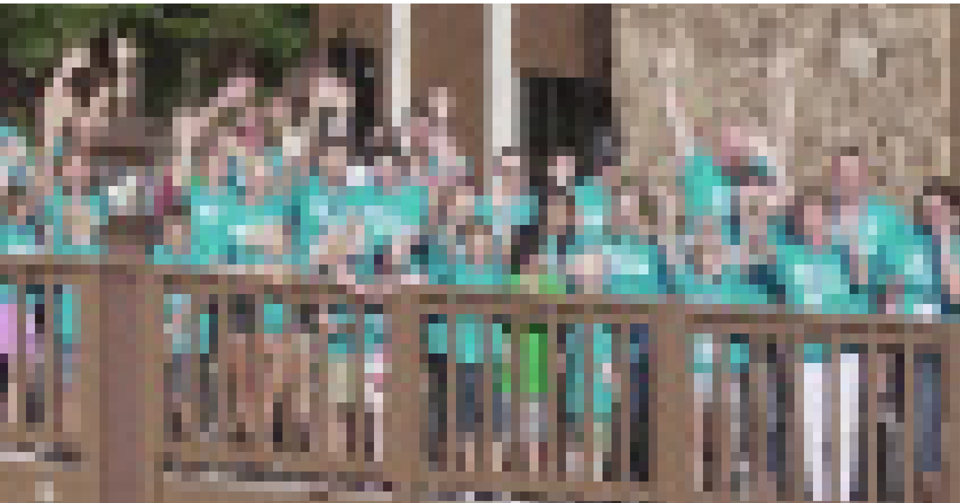
EDUCATION

The NFED offers a range of educational resources and events to meet the changing needs of people affected by the different types of ectodermal dysplasias.

And by connecting you with families like yours, the NFED also gives you the opportunity to learn from one another.

RESEARCH

The NFED encourages and supports medical, dental, genetic, and other ectodermal dysplasia—related research to improve the health and quality of life of people living with ectodermal dysplasias, and, ultimately, to find cures.



SUPPORT

The NFED provides lifelong support for individuals and families affected by ectodermal dysplasias by:

- Offering personalized service and support to families affected by ectodermal dysplasias, particularly those with recently diagnosed children
- Helping families understand currently available treatment choices
- Partnering with doctors and dentists to ensure that the most effective care is being offered
- Working with families to find appropriate financial assistance
- Helping secure insurance coverage for dental and medical treatment related to ectodermal dysplasias

> **“THE NFED HAS BEEN MY LIFESAVER … I FINALLY KNEW I WAS NOT ALONE. THERE WERE OTHERS LIKE ME.” — TERRI, INDIVIDUAL AFFECTED BY ECTODERMAL DYSPLASIA**

JOIN US. GET INVOLVED. **MAKE A DIFFERENCE.**

At the NFED, we are committed to building a strong community of people to help those living with ectodermal dysplasias. Our goal is to get everyone active and engaged!

There are so many ways for you to get involved and make contributions to the community in ways that fit your talents, interests, comfort levels, and availability.

By offering your time, money, and support, you can help us make this community all that we need and want it to be.