

Ectodermal Dysplasias

Fact Sheet

What are the ectodermal dysplasias?

- The ectodermal dysplasias are a group of heritable disorders which are characterized by at least two derivatives of the ectoderm. (i.e. teeth, hair, nails, glands) developing and functioning abnormally.
- There are at least 150 different ectodermal dysplasias based on the combination of symptoms an individual has. Symptoms range from mild such as a missing tooth and thin hair to more severe such as skin erosion.

What causes the ectodermal dysplasias?

The ectodermal dysplasias are the result of a genetic mutation passed from parent to child. In some cases, the genetic mutation occurs spontaneously in the affected person. The ectodermal dysplasias are not contagious.

How many people are affected by ectodermal dysplasias?

We are not certain. We do know, however, that many more people are affected by ectodermal dysplasias than was ever thought possible. The number is estimated as high as 7 in 10,000 births (published in the 1990 edition of The Birth Defects Encyclopedia).

How do the ectodermal dysplasias affect people physically?

- Individuals affected by ectodermal dysplasias frequently have abnormal hair. Scalp and body hair may be thin, sparse, and very light in color, even though beard growth in affected males may be normal. The hair may be excessively brittle, curly, or even twisted.
- Fingernails and toenails may be thick, abnormally shaped, discolored, ridged, slow-growing, or brittle. The cuticles may be prone to infections.
- The skin may be lightly pigmented. In some cases, red or brown pigmentation may be present. Skin can be prone to rashes or infections and can be thick over the palms and soles.
- Many individuals affected by ectodermal dysplasias cannot perspire. Their sweat glands may function abnormally or may not have developed at all. Without normal sweat production, the body cannot regulate temperature properly.
- Abnormalities in the development of tooth buds usually result in missing teeth or in the growth of teeth that are peg-shaped or pointed. The enamel may also be defective.

How do the ectodermal dysplasias affect lives?

- Many individuals affected by ectodermal dysplasias cannot perspire. Air conditioning in the home, school and work place is a necessity.
- Most people with ectodermal dysplasias have missing or malformed teeth. Dental treatment is necessary, beginning with dentures as early as age two, multiple replacements as the child grows and perhaps dental implants thereafter. Orthodontic treatment may also be necessary.
- Precautions must be taken to limit upper respiratory infections and care must be provided for the skin to prevent cracking, bleeding and infection.

National Foundation for Ectodermal Dysplasias

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The National Foundation for Ectodermal Dysplasias (NFED) is the only organization in the United States dedicated to supporting families affected by the ectodermal dysplasias. The ectodermal dysplasias are a group of rare disorders in which the teeth, hair, nails and glands develop and function abnormally.

Mission

The NFED empowers and connects people touched by ectodermal dysplasias through education, support and research.

Services

Dental Treatment Centers Program	Publications on Treatment and Care
Ectodermal Dysplasias International Registry	Referrals
Family to Family Network	Research Program
Informational Literature	Scholarship Program
Bi-Monthly Newsletters	Treatment Assistance Program
Medical Guide Series	
National and Regional Family Conferences	

Incorporation

December 24, 1981 - Mascoutah, Illinois as a 501(c)3 organization

Number of People Served

More than 5,800 individuals affected by the ectodermal dysplasias in 50 states and 70 countries

Fiscal Year

January - December

Annual Budget

\$1,300,000

Funding

The NFED spends 86 cents of every dollar raised on family services, education, research and treatment assistance. Funds are raised through private contributions, special events and foundation grants.

Staff

Executive Director: Mary K. Richter
Director of Development: Carol Agne
Director of Family Support and Outreach: Kelley M. Atchison
Director of Public Relations: Jodi Edgar Reinhardt
Director of Research: Mary Fete, RN, MSN, CCM
Director of Institutional Advancement: Harry Ford
Director of Education: Malinda K. Heuring
Director of Finance and Records: Beverly A. Meier
Office Administrator: Jackie Schmitz



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