

ECTODERMAL DYSPLASIAS

Fact Sheet

What are ectodermal dysplasias?

Ectodermal dysplasias are a diverse group of genetic disorders that involve defects of the hair, nails, teeth, skin and glands. Other parts of the body, such as the eyes or throat, may be affected as well. The combination of physical features a person has and the way in which it is inherited determines if it is an ectodermal dysplasia. More than 180 different types of ectodermal dysplasias exist. Yet, most types share some common symptoms, ranging from mild to severe.

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 do not know for sure. An estimated 3.5 of 10,000 people are affected by ectodermal dysplasia. Ectodermal dysplasias are considered “rare” conditions because they affect less than 200,000 people in the United States. This rarity makes an official study to determine numbers difficult and costly.

Does ectodermal dysplasia impact learning abilities?

Cognitive ability is normal in nearly all types of ectodermal dysplasia.

Does ectodermal dysplasia affect lifespan?

Lifespan is normal in nearly all types of ectodermal dysplasia.

Is ectodermal dysplasia found in one race more frequently than another?

No. Ectodermal dysplasias can affect a person of any race.

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 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.



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