



NEWS RELEASE

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Fun Walk Benefits Local Charity Rare Genetic Disorder

MASCOUTAH, Ill.— The National Foundation for Ectodermal Dysplasias is walking forward. Their newly added countrywide fundraisers, Don't Sweat It Walks, are still going on, this time in Edwardsville, Ill. The walk will take place Saturday, November 3 on the campus grounds of Southern Illinois University Edwardsville.

Registration for the walk starts at 7:30 a.m. with the 5K walk starting at 8 a.m. Registration is \$25 and includes a Don't Sweat It Walk t-shirt. Participants can register online at nfed.org or contact the NFED office at 618-566-2020. Free parking for the event is available in Lot10. Visit siue.edu/parking for a map of the location. Look for Don't Sweat it walk signs to help guide you.

The theme, Don't Sweat It, reflects the NFED's philosophy: while the ectodermal dysplasias present challenges, families shouldn't worry; they can expect for their children to live the lives they dreamed. Ectodermal dysplasias? Don't Sweat It!

The NFED is a national nonprofit organization with its headquarters located in Mascoutah, Ill., about 45 min southeast of Edwardsville. The organization helps support individuals and their families affected by ectodermal dysplasias. Ectodermal dysplasias are rare genetic disorders affecting the hair, teeth, nails and sweat glands.

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Proceeds from the walk will help the NFED continue their mission to, “To empower and connect people touched by ectodermal dysplasias through education, support, and research.”

About the Ectodermal Dysplasias

The ectodermal dysplasias are genetic conditions that involve defects in the hair, teeth, nails and sweat glands. Other parts of the body also may be affected. There are more than 150 different ectodermal dysplasias which are recognized by the combination of physical features an affected person has and the way they are inherited. Symptoms can range from mild to severe. Hypohidrotic ectodermal dysplasia is the most common syndrome and features multiple malformed and missing teeth, the inability to perspire and sparse hair. Only in rare cases does ectodermal dysplasia affect lifespan and very few types involve learning difficulties. The ectodermal dysplasias affect men, women and children of all races and ethnic groups. According to the *Birth Defects Encyclopedia* as few as one or as many as 7 in 10,000 babies are born affected by an ectodermal dysplasia.

About the National Foundation for Ectodermal Dysplasias (NFED)

The NFED is the leading resource in the world serving the ectodermal dysplasias community. The mission of the NFED is to empower and connect people touched by ectodermal dysplasias through education, support and research. Located in Mascoutah, Ill., the Foundation is in contact with more than 6,000 families in 75 countries. Seventy-five cents of every dollar raised is spent on education, support and research. The NFED is a private, tax-exempt, not-for-profit organization pursuant to section 501(c)(3) of the Internal Revenue Code.

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