

FAMILY LIAISON PROGRAM

A Caring Community Who Understands Where You Are

We know there's a chance that you have never met another person affected by ectodermal dysplasias. We understand that because of this, you may feel that you are all alone in your journey.

We have created a support network of Family Liaisons to give you the opportunity to talk to others who have experience living with ectodermal dysplasias, and to share your feelings with others who understand.

Family Liaisons are volunteers who are affected by ectodermal dysplasia or who are the parent of an affected child.

Family Liaisons provide moral support, information and practical advice, guidance, education, resource information and increase awareness and events for families.

We encourage you to reach out to the Family Liaison either in your state or the same syndrome.

Ankyleblepharon-Ectodermal Defects-Cleft Lip and/or Palate (AEC) Syndrome



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Ectrodactyly-Ectodermal Dysplasia-Clefting (EEC) Syndrome



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Focal Dermal Hypoplasia (Goltz)



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Hypohidrotic Ectodermal Dysplasia (HED)



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Would You Like to Be A Family Liaison?

If you want to volunteer to support other families, please contact:

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