

Our Mission ...

To enhance the quality of life of those impacted by ectodermal dysplasia's through education, service, and advocacy while serving as a national information and support resource.

Our Vision ...

The Canadian Ectodermal Dysplasia Syndromes Association (CEDSA) is your national information and resource centre on provincial and territorial funding programs, medical expertise, ongoing research and support groups. Working with established ectodermal dysplasia associations around the world, CEDSA supports research towards a cure, raising awareness of EDS and connecting children, youth, family and friends.

The Canadian
Ectodermal Dysplasia
Syndromes Association

Association canadienne des
syndromes dysplasie
ectodermique

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Canadian
Ectodermal Dysplasia
Syndromes
Association



Ectodermal dysplasia syndromes are a large group of inherited disorders that result in the abnormal development of the teeth, skin, nails, hair, sweat glands, and the cranial-facial structure. If an individual has two or more of these abnormalities, they are considered to have an ectodermal dysplasia syndrome.

Dental abnormalities include, among others: missing or absent teeth, square or cone-shaped teeth, and cleft lip/palate. Individuals face a life-time of dental work, and may have to rely on dentures from a very young age.

People with an ectodermal dysplasia syndrome may suffer from skin erosions, eczema, thickening of the skin, cracking, and overall skin fragility. Nails can be missing, deformed and slow to grow.

Hair is also often absent and can be very sparse, curly or twisted and is often lightly pigmented. Fingers and toe digits can be malformed or cleft.

Many ED syndromes are also characterized by an inability or reduced ability to sweat, making staying cool a challenge. This is of particular concern

if the person gets a fever as their body does not cool on its own.

Facial characteristics vary but can include a saddle-bridge nose, small nostrils, prominent forehead, and cupped or malformed ears.

While there is currently no cure, it is important to note that life-span is normal for the majority of conditions and is not characterized by developmental delays. Individuals with an ectodermal dysplasia syndrome live happy, active and full lives despite special medical needs.



About Us

The Canadian Ectodermal Dysplasia Syndromes Association (CEDSA) was established in April 2010 by executive director Meghan Howard to answer a need for information and services geared to Canadians and their families on national funding and resources. Around the world there are a number of well-established and excellent associations providing information, funding research and acting as leaders for families affected by EDS.

Management of CEDSA is being donated by Megram Consulting Services Ltd. of Renfrew.

Volunteers Needed



An association is, by definition, an organized body of people who share a common interest, activity or purpose. As a new association, we are looking for those interested in contributing in any and all capacities and / or supporting the association through membership. From writing for the newsletter to providing information and research to joining our board, we'd be interested in hearing from you.

**Contact Meghan Howard today at
meghan@megram.com
or call 613-432-9491.**

Membership

Join CEDSA today!
Your \$20 membership fee will go towards support of The Canadian Ectodermal Dysplasia Syndromes Association. Please indicate if you would like to receive our newsletter.

Name: _____

Address: _____

Email: _____

Please enclose cheque or money order to Megram Consulting Services, CEDSA membership or register on-line at www.ectodermadysplasia.ca

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