



Charity No: 1089135

## Ectodermal Dysplasia Society

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### From the Ectodermal Dysplasia (ED) Society

The ED Society is delighted that two Tonbridge school girls have offered to donate their hair to one of the Society's members. This will be the first ever hair cut for Sophie Blanch, 15, who has been growing her hair since birth, and Ciara Tringham, 16, has only ever had her hair cut once before. The girls were put in touch with the ED Society via C27 Media, the company presently re-developing the ED Society website, when they discovered that some sufferers of ectodermal dysplasia have missing or very sparse hair. As the girls have enjoyed having beautiful hair throughout their childhood and teenage years, they thought it would be nice to give a child who is not so fortunate the chance to have lovely hair too, so they have offered to have their hair cut short and donate it to be made into a wig for one of our young members who has Rapp-Hodgkin which is a very rare ED syndrome. Those affected by ED are born without sweat glands and are unable to wear the synthetic wigs offered by the NHS as they can cause overheating. In addition, the NHS does not provide wigs specifically for children but cuts adult wigs down to child size which can often look rather strange on a child.

ED is not a single disorder, but a group of closely related conditions of which more than 150 different syndromes have been identified. The Ectodermal Dysplasias are genetic disorders affecting the development or function of the teeth, hair, nails and sweat glands. Depending on the particular syndrome ED can also affect the skin, the lens or retina of the eye, parts of the inner ear, the development of fingers and toes, the nerves and other parts of the body.

ED is a life threatening condition and living with it provides family with many challenges. The most common form of ED, which is still in itself a rare disorder, is Hypohidrotic Ectodermal Dysplasia. Individuals with this condition have an inability to sweat due to absent or reduced sweat glands and therefore risk overheating at any time of year, either from atmospheric temperatures or an impending infection. Those affected by ED also have problems in the winter months maintaining adequate body temperature, i.e. they get too cold and have difficulty in warming up.

Due to the malfunction of certain glands eg. mucous membranes, saliva glands, in the nose, larynx, trachea and lungs, many adults and children with this condition are prone to croup, bronchitis, asthma and other respiratory problems. Individuals also suffer with extremely dry skin and eczema requiring oil baths and skin moisturisers 2/3 times a day.

Another major symptom of ED is the almost total absence of any teeth while those teeth that are present are very pointed. Due to the absence of teeth the individual will be required to make many visits to a dentist or dental hospital to have dentures made for them at as young as 3 years of age and later in life have implants fitted.

As we have said before, Ectodermal Dysplasia is a rare genetic condition and as such many medical professionals, health officials, education professionals and the public have never heard of it. Many parents of children with an ectodermal dysplasia syndrome find the day to day management of the condition is not only very time consuming, but very frustrating when the medical profession have no experience of ED.

The ED Society aims to raise the awareness of ED among people in the UK and Ciara and Sophie are helping us to that today. The girls have launched a fundraising campaign to coincide with the venture and have already raised money from fellow pupils at their school. If you would like to help the ED Society please visit our website at [www.ectodermaldysplasia.org](http://www.ectodermaldysplasia.org) or write to Diana Perry at The ED Society, 108 Charlton Lane, Cheltenham, Glos GL53 9EA.

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