



Ectodermal Dysplasia Syndrome Symptoms Questionnaire

Charity No: 1089135

Name of Person with ED _____

Address: _____

Telephone No. _____ Email Address: _____

Date of Birth _____

Male/female _____ Date Completed _____

Type of ED: _____

Has a specific diagnosis for this type of ED been made? Yes/No

Who made the diagnosis - Geneticist, Dermatologist, Dentist,
 GP Doctor or someone else? (please circle)

Please complete the following questions as completely as possible. If we have not left enough room for your answers please use the end of the questionnaire or a separate sheet

Please note these questions cover many of the Ectodermal Dysplasia different syndromes, therefore, not all questions will be applicable to you or your child.

Teeth

Small, Pointed or missing teeth? (please circle)

How many teeth in total? Adult - Top _____ Bottom _____
 Baby - Top _____ Bottom _____

Dental Implants - how many - top/bottom? _____

Bone Grafting top/bottom? _____

Cleft Palate and/or cleft lip?

Poor/weak enamel?

Discolouration?

Mouth ulcers/blisters?

Any other teeth problems?

If yes, what are they?

Yes	No	Unknown

Hair

Absent, sparse, patchy scalp hair? (please circle)
Scalp infections?
Thin, fine, brittle, dry, slow growing, unmanageable, curly, straight, brown, black, blond, red? (please circle which type/colour)
Wig - synthetic, natural hair - NHS or private? (please circle which apply)
Any other problems with hair and any successful treatments?
If yes what are they? _____

Yes	No	Unknown

Eyes

Few or no tears, dry eyes, treatment used? _____
Blocked/missing tear ducts? _____
Any corrective tear duct surgery, if so what? _____
Sparse or missing eyebrows?
Sparse or missing eyelashes?
Ingrowing eyelashes?
Recurrent conjunctivitis or blepharitis?
Any retinal scarring (including peripheral)?
Retinal detachment?
Ever had laser treatment to contain bleeding of blood vessels?
Squint?
Astigmatism?
Any other eye or vision problems and any successful treatments?
If yes, what are they? _____

Yes	No	Unknown

Ears, Nose & Throat

Nerve or other deafness?
Ear wax - normal or impacted? (please circle)
Grommets - one or both ears? _____
Bad smelling nasal discharge?
Nosebleeds frequent/occasional/severe/mild? (please circle which applies)
Frequent colds and/or respiratory tract infections?
Large amounts of phlegm?
Any other problems with ear, nose or throat and any successful treatments?
If yes, what are they? _____

Yes	No	Unknown

Sweat Glands

Decreased or absent sweating?
Excessive sweating?
Lack of temperature control?
Restricted activity due to heat intolerance?
Frequent high fevers?
Do you wear cooling jacket or something similar?
Behavioural problems associated with overheating?
Any other temperature problems and any successful treatments?
If yes, what are they? _____

Yes	No	Unknown

Breasts - underdeveloped, missing - one or both? (please circle)
 Nipples - unusual, missing - one or both? (please circle)
 Delayed sexual development?
 Males - beard growth - normal, patchy missing? (please circle)
 Learning difficulties?
 Lack of Concentration?
 Delayed mental or physical development?
 Speech problems? Please specify
 Mobility problems? Please specify
 Any other problems with growth & development or with the skeleton or limbs?

Any Allergies? If yes, what are they? _____

Digestion

Feeding problems, breast or bottle, poor weight gain, gastroesophageal reflux? (please circle)
 Frequent vomiting or swallowing difficulties? (Please circle)
 Constipation, severe/mild? (please circle)
 Bladder problems?
 If yes, what are they? _____

Yes	No	Unknown

Any infant or early childhood deaths in the family?
 Did the child who died have ED? _____

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List any other birth defects or health problems both past and present.

Other relatives, living or deceased, with any problems arising from the above questions?
 Problem: _____

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Person completing the questionnaire: _____

Relationship to person named on page 1: _____

Thank you for taking the time to complete this questionnaire

Please return your form to:

The Ectodermal Dysplasia Society, 108 Charlton Lane, Cheltenham, Glos. GL53 9EA.
 Tel: 01242 261332 Email: diana@ectodermaldysplasia.org
 Website: ectodermaldysplasia.org