



Ectodermal Dysplasia Questionnaire

Please return your completed form to: The ED Society, Unit 1 Maida Vale Business Centre,
Cheltenham, Glos. GL53 7ER England

Name: _____

Address: _____

Name of person with ED: _____

Relationship to person with ED: _____

Male/female: _____ Date of Birth: _____

Date Completed: _____ Telephone No. _____

Email Address: _____

DLA / CA / AA

Do you receive Disability Living Allowance If no, have you ever applied
Carer's Allowance If no, have you ever applied
Attendance Allowance If no, have you ever applied

Did you Appeal or attend a Tribunal? If yes, what was the outcome?
.....

Which rate do you receive.....

Disability Living Allowance high rate middle rate low rate
Care Component high rate middle rate low rate
Mobility component high rate low rate
Carer's Allowance
Attendance Allowance

Any other allowance linked to ED, please list:

The Ectodermal Society, Unit 1 Maida Vale Business Centre, Cheltenham, Glos. GL53 7ER England
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Please complete the following questions as fully as possible. If we have not left enough room for your answers please use 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.

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, (Please circle)? If someone else please state

Teeth

- Adult Upper jaw no. lower jaw no.
- Baby Upper jaw no. lower jaw no.
- Pointed
- Missing teeth
- Dental Implants how many Top Bottom
- Bone Grafting upper jaw lower jaw
- Dentures upper jaw lower jaw full partial
- Cleft Palate
- Cleft lip
- Weak enamel
- Enamel discolouration
- Mouth ulcers

If over age 10 do you still have baby teeth? How many Top Bottom

Any other teeth problems? If yes, what are they?

Ears, Nose & Throat

- Nerve or other deafness?
- Hearing Aid left ear removable fixed
right ear removable fixed
- Ear wax normal Impacted
- Ear canal normal narrow misshapen
- Grommets left ear right ear
- Bad smelling nasal discharge
- Nosebleeds frequent occasional severe mild
- Nasal reconstruction
- Frequent colds
- Respiratory tract infections frequent occasional
- Large amounts of phlegm thick fluid
- Lack of saliva
- Choking
- Sensitive Hearing

Any other problems with ear, nose or throat and any successful treatments? If yes, what are they?

Sleep

- Difficulty getting to sleep
- Difficulty waking up
- Wake regularly during the night
- Bedwetting

Nails

- Poor nails on hands brittle weak ridged flaky
small unusual slow growing
- Poor nails on feet brittle weak ridged flaky
small unusual slow growing
- Recurrent infections

Any other nail problems and any successful treatments
 If yes, what are they?

Hair

- Scalp hair absent
 sparse
 patchy
 type - thin fine brittle dry straight
 curly brown black blonde red
 slow growing unmanageable
- Wig
 synthetic NHS private
 natural hair NHS private
- Scalp infections

Any other problems with hair and any successful treatments?
 If yes, what are they?

Joints/Muscles

- Muscle weakness affected by hot weather cold weather
- Regular joint aches affected by hot weather cold weather
- Painful legs
- Constant fidgeting

If yes, please explain how you are affected

Digestion

- Feeding problems breast bottle poor weight gain
- Gastroesophageal reflux
- Vomiting frequent occasional
- Swallowing difficulties
- Constipation severe mild
- Bladder small large
- Incontinence severe mild
- Aspiration

Sweat Glands

- Sweating decreased absent excessive
- Lack of temperature control
- Restricted activity due to heat intolerance due to cold intolerance
- Frequent high fevers
- Behavioural problems associated with heat associated with cold
- Cooling aids jacket vest fans hat
 Air-conditioning Chillowpillow Blanket
- Any other temperature problems if yes, what are they
- Successful treatments if yes, what were they

Eyes

- Blocked tear ducts
- Absent tear ducts
- Treatment used
- Tears few no tears dry eyes
- Corrective tear duct surgery if so what?
- Recurrent conjunctivitis
- Blepharitis
- Squint
- Retinal detachment
- Astigmatism
- Eyebrows Absent Sparse Normal
- Eyelashes Absent Sparse Normal
- In-growing eyelashes
- Any retinal scarring (including peripheral)
- Laser treatment to contain bleeding of blood vessels
- Any other eye or vision problems if yes, what are they
- Successful eye treatments if yes, what were they

Skin

- Body skin condition dry thin cracks/splits easily
- Recurrent body skin infections
- Scalp infections severe mild
- Scalp crusting severe mild
- Eczema severe mild
- Bruise easily
- Thickened skin on soles of feet severe mild
- Thickened skin on palms of hands severe mild
- Skin/tissue slow to heal
- Blisters as baby skin infections as a result of blisters
- Pigmentation marks where
- Age pigmentation marks appeared
- White scarring marks (later stage) where
- Age scarring marks appeared
- Any changes in skin if unwell

Sensitive skin

Any other skin problems if yes what are they

Successful treatments if yes, what were they

Other problems

Seizures frequent occasional

Blackouts (fainting) frequent occasional

Fingers missing extra webbing

Toes missing extra webbing

Short stature

Growth problems growth hormones

Breasts left underdeveloped left absent
 right underdeveloped right absent

Nipples left unusual left absent
 right unusual right absent

Delayed sexual development

Beard growth normal patchy missing

Learning difficulties

Lack of Concentration

Delayed mental development

Delayed physical development

Speech problems please specify

Mobility problems please specify

Allergies if yes, what are they

Any other problems with the skeleton or limbs?

Infant or early childhood deaths in the family if yes, at what age did they die

Did they have ED? Yes No Unknown

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

.....

Relatives, living or deceased, with any problems arising from ED? Yes No Unknown

If yes, please state the problem

Can you recommend a Dentist

Hospital or address

Geneticist

Hospital or address

Dermatologist

Hospital or address

Any other specialist