

# Client Survey

1. Name of person affected by an ectodermal dysplasia syndrome \_\_\_\_\_

2. Street \_\_\_\_\_

City

State or Province

E-mail Address

Country

Postal Code

3. Date of Birth \_\_\_\_\_

4. Telephone Number \_\_\_\_\_

5. Male

6. Female

Date Completed \_\_\_\_\_

**Please attach recent photo.**

Are you willing to allow the NFED to share the above contact information with other affected families?

\_\_\_\_\_yes

\_\_\_\_\_no

<b>Please answer each question.</b>
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		YES	NO	UNKNOWN
7.	Small, pointed or missing teeth			
8.	Dental implants			
9.	Cleft palate and/or cleft lip			
10.	Other problems with the teeth			

If yes, what are they?  
\_\_\_\_\_  
\_\_\_\_\_

11.	Absent or sparse scalp hair			
12.	Slow growing, fragile or hard to manage hair			
13.	Other problems with hair			

If yes, what are they?  
\_\_\_\_\_  
\_\_\_\_\_

14.	Few or no tears			
15.	Sparse or missing eyebrows or eyelashes			
16.	Other eye or vision problems			

If yes, what are they?  
\_\_\_\_\_  
\_\_\_\_\_

17.	Nerve or other deafness			
18.	Too much ear wax			
19.	Bad smelling nasal discharge			
20.	Frequent colds, pneumonia and/or respiratory tract infections			
21.	Other problems with the ear, nose or throat			

If yes, what are they?  
\_\_\_\_\_  
\_\_\_\_\_

22.	Decreased or absent sweating			
23.	Restricted activity due to heat intolerance			
24.	Frequent high fevers			
25.	Dry skin			
26.	Other chronic skin problems			

If yes, what are they?  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

		YES	NO	UNKNOWN
27.	Small, unusual or slow growing nails			
28.	Small, extra or absent fingers or toes			
29.	Short stature			
30.	Underdeveloped, missing or extra nipples			
31.	Delayed sexual development			
32.	Other problems with growth and development or with the skeleton or limbs			

If yes, what are they?

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33.	Feeding problems, poor weight gain, gastroesophageal reflux, frequent vomiting or swallowing difficulties			
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If yes, what are they?

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34.	Has a specific diagnosis for this type of ED been made?			
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If yes, what is it? Please check the appropriate type of ED

- Ankyloblepharon-ED-Clefting AEC (Hay-Wells Syndrome)  
 Ectrodactyly-Ectodermal Dysplasia-Clefting (EEC Syndrome)  
 Focal Dermal Hypoplasia (Goltz Syndrome)  
 Hidrotic Ectodermal Dysplasia (Clouston Syndrome)  
 Hypohidrotic Ectodermal Dysplasias (HED)  
 Incontinentia Pigmenti (IP)  
 Rapp-Hodgkin's Syndrome (RHS)  
 Trichorhinophalangael (TRP Syndrome I)  
 Witkop's Tooth Nail Syndrome  
 Other \_\_\_\_\_  
 Unknown

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

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

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38. Other relatives, living or dead, with any of the problems mentioned in the previous questions.

RELATIONSHIP	NAME(OPTIONAL)	PROBLEMS
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39. Names and addresses of professionals whom you would recommend to others.

NAME	ADDRESS	AREA OF SPECIALTY
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Full Names of Parents or Guardians (if patient affected by ED is under age 18)

Father

Mother

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Guardian(s)

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PLEASE RETURN THIS FORM AND PHOTO TO:

**National Foundation for Ectodermal Dysplasias**  
 410 East Main Street, P.O. Box 114  
 Mascoutah IL 62258-0114 USA

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