HED Medical Questionnaire

- *If you are 18 years old or older this questionnaire should be completed on your own.*
- *If the patient is under the age of 18 a parent or legal guardian should complete this questionnaire answering all questions for the child.*

Participant's Initials: ☐☐☐

Participant's ID #: ☐☐☐
*To be completed by study personnel

Today's Date: ☐☐/☐☐/☐☐☐☐

Date of birth: ☐☐/☐☐/☐☐☐☐
Month/Day/Year

Are you currently experiencing any major medical problems that would prevent you from participating in this study? ☐Yes ☐No

Do you have a known hypersensitivity to pilocarpine or pilocarpine-like muscarinic agonists (Examples: Urecholine, Salagen, Pilocar, and Provocholine)? ☐Yes ☐No

Do you have a known hypersensitivity to lidocaine or lidocaine like agents? ☐Yes ☐No

Do you have a pacemaker? ☐Yes ☐No

Height & weight estimates Ht ☐Ft ☐☐In Wt ☐☐☐Lbs

Are you participating as a: ☐Unaffected Male ☐HED affected male

Have you been diagnosed with HED? ☐Yes ☐No

If yes, age at diagnosis: ☐0-5 years ☐6-17 years ☐≥18 years

Do you have any family members diagnosed with HED? ☐Yes ☐No

If yes, check all that apply:
☐Mother
☐Father
☐Sisters
☐Brothers
☐Aunts
☐Uncles
☐Other

If other, specify:

Have you or any family member(s) had genetic testing for HED? ☐Yes ☐No

Do you know the genetic test results? ☐Yes ☐No

Do you have decreased sweating? ☐Yes ☐No

Do you have unexplained fevers? ☐Yes ☐No

Did you ever suffer from seizures associated with fever? ☐Yes ☐No

Do you suffer from heat intolerance? ☐Yes ☐No

Is your exercising limited by heat intolerance? ☐Yes ☐No

Does your decreased sweating/heat intolerance affect your:
**Check all that apply*

- ☐Daily life
- ☐Choice of occupation
- ☐Involvement in indoor sports
- ☐Involvement in outdoor sports
- ☐Decision to live in cooler climate
- ☐Choice of vacation destinations
- ☐Ability to travel

Have you experienced hair or eyebrow thinning or hair loss? ☐Yes ☐No

If yes, what age were you when you noticed the loss of hair? ☐0-5 yrs ☐6-10 yrs ☐11-17 yrs ☐≥18 yrs

How often do you get your hair cut? Once every: ☐☐ Months

Do you get haircuts less often than unaffected siblings/ classmates? ☐ Yes ☐ No

Have you ever tried a topical treatment to reduce hair thinning? ☐Yes ☐No

How interested would you be interested in trying a new treatment to reduce/delay hair thinning?

1	2	3	4	5
☐	☐	☐	☐	☐

No Interest Strong Interest

Do you have problems with your teeth (no teeth, missing or misshapen teeth)? ☐Yes ☐No

If yes, describe age of treatment with dentures and/or implants if applicable (check all that apply):

	Dentures	Implants
1-5 years	☐	☐
6-10 years	☐	☐
11-17 years	☐	☐
≥18 years	☐	☐

What foods are challenging to eat or do you avoid for dental reasons? _____

To the best of your knowledge how many baby teeth did you develop? ☐☐

To the best of your knowledge how many adult teeth did you develop? ☐☐

Do you suffer from dry mouth? ☐Yes ☐No

Do you suffer from dry eyes? ☐Yes ☐No

If vision correction is needed, are you able to wear contacts?	☐Yes	☐No
Do you require eye drops on a regular basis?	☐Yes	☐No
Do you suffer from frequent eye infections?	☐Yes	☐No

Did you have chronic nasal drainage/blockage as a child?	☐Yes	☐No		
If yes, were you ever hospitalized for antibiotic therapy?	☐Yes	☐No		
Did you suffer from nosebleeds as a child?	☐Yes	☐No		
If yes, at what age did you first notice them?	☐0-5 yrs	☐6-10 yrs	☐11-17 yrs	☐≥18 yrs
Do you still experience nosebleeds?	☐Yes	☐No		
How many times per year do you have nosebleeds?				
Did you have respiratory related problems as a child?	☐Yes	☐No		
If yes, were you ever hospitalized for antibiotic therapy?	☐Yes	☐No		
Do you suffer from sinus infections most years?	☐Yes	☐No		
If so, at what age did these sinus infections start?	☐0-5 yrs	☐6-10 yrs	☐11-17 yrs	☐≥18 yrs
Do you suffer from asthma?	☐Yes	☐No		
If so, do you require medication to manage your asthma?	☐Yes	☐No		
Do you experience a hoarseness of your voice?	☐Yes	☐No		
If yes, at what age did you first notice it?	☐Yes	☐No		
Is the hoarseness worse during the cold months?	☐Yes	☐No		

Do you have problems with dry skin or eczema?	☐Yes	☐No
If yes, have you tried prescription medications?	☐Yes	☐No
If yes, list medications:		
Do you have a family history of eczema (other than XLHED males)?	☐Yes	☐No
Do your fingernails and/or toenails appear normal?	☐Yes	☐No
Do your fingernails and toenails grow faster than other family members?	☐Yes	☐No