FREQUENTLY ASKED QUESTIONS

Research Project: Ectodermal Dysplasia – Type Unknown

Dr. Richard A. Lewis provided answers to some questions regarding this project.

Q. My child/myself are considering participating in this research, how long will the process take at conference?

**Dr. Lewis:** The researchers may spend 30 minutes or more collecting contact information, developing a pedigree, provide a Family History Questionnaire to fill out and return, provide a standard Release of Protected Health Information forms to collect medical records, discuss the Consenting Process and answer any questions.

Q**.** Will my child/myself need to provide a blood sample at conference?

**Dr. Lewis:** There will be no blood samples taken at conference, however we will ultimately need blood samples from both parents and the individual affected by Ectodermal Dysplasias. In dominant families this may be modified by including two consecutive generations, or three if the affected grandparent is living.

Q. My child/myself has had a prior genetic evaluation (6 years or so ago.) Would we bring those results to be analyzed further?

**Dr. Lewis:** The doubling time of information in this field is about 2 years. As part of the standard Release of Protected Health Information, we will hope to recover all the relevant medical information on the Ectodermal Dysplasias related features on each person. Prior genetic reports are useful to see 1) what was done; 2) by what laboratory; 3) by what technology; 4) with what results (and exclusions). We will not reanalyze old specimens.

Q. When would results be returned/shared with the family?

**Dr. Lewis:** In the Consent for Participation which everyone who participates must sign (or parent or guardian for minor children), several options are available: 1) I do NOT wish to be informed; 2) I do wish to be informed of the results relevant to the condition for which I joined the study; 3) I do wish to be informed of results relevant to my health OTHER THAN the condition for which I joined the study: 4) I want to think about it and decide later. So every family and enrollee may choose.

Q. If we participate in the study/diagnosis offer would we, or could we continue further contact with this doctor?

**Dr. Lewis:** As long as the researcher is available, yes; The Directors of the laboratory doing the actual work will continue and the research results are open to discussion.

Q. How would breakthroughs be shared with families participating?

**Dr. Lewis:** At the individuals request on the Consent Statements, the research results will be shared in writing with each participating family; a genetic counsellor is a part of the program and each participant may pose questions and will be counselled to the results. However, we do request, and each participant will be asked to consent, to anonymous publication of results and release of anonymous new gene or mutation discoveries in public databases so all of medicine will be informed by new information.

**Q. Do we have to** attend **the conference to have the evaluation?**

**Dr. Lewis:** No. We can do much of the evaluation by telephone, however participants must share all relevant medical records and some photographs so that we may “see” features that are difficult to describe in words.

Q. **Could we send in our genetic report and photos for further evaluation?**

**Dr. Lewis:** As noted above, these records are essential to see what has been done, in what era they were done, in what lab they were done, and what the interpretation was submitted. Photos of the characteristic features of each affected person is essential, especially if there are several “unknown” or “unsolved” individuals who show similar features that allow for identification of new causes of ectodermal dysplasia.