



UNDERSTANDING CS, TTD, and A-T

My name is Valerie Natale. I work for the Forgotten Diseases Research Foundation.

I'm asking you to take part in a research study because I'm trying to learn more about CS, TTD, and A-T. I want to learn about what goes wrong in these disorders.

If you agree, I'll ask you some questions and maybe ask for a blood sample. Your mum or dad or someone else can help you answer them. The questions are about your medical problems. I'll also ask your mum or dad some questions about you, like your height and weight, and how much you weighed when you were born, how you've grown, and other questions. I'm trying to learn as much as I can about these conditions so that I can help other people like doctors understand them.

You don't have to be in this study. No one will be mad at you if you decide not to do this study. Even if you start, you can stop later if you want. You can ask questions about the study.

If you decide to be in the study I won't tell anyone else what you say or do in the study.

Write your name here if you've read this form (or had it read to you) and you want to be in this study.

Signature of subject _____

Subject's printed name _____

Signature of investigator _____

Date _____