

CONSENT TO PARTICIPATE IN RESEARCH

1. Dr. Valerie Natale from the Forgotten Diseases Research Foundation (FDRF) is studying how CS, TTD, and A-T develop. I've been asked to participate because I or my child has one of these conditions.
2. If I agree to be in this study, Dr. Natale or another researcher from the Forgotten Diseases Research Foundation will interview me briefly and ask for medical records.
3. Dr. Natale may also ask for volunteers to provide blood samples. These samples will be sent to a certified testing lab for standard testing (complete blood count, chemistry panels, etc.).
4. The FDRF will be happy to share test results with parents/guardians.
5. The FDRF hopes to publish results related to this study so that many people with these disorders will benefit from this work. However, we will not release personally identifiable information about anyone who takes part in this study.
6. I may contact Dr. Natale as follows:

c/o Forgotten Diseases Research Foundation
 604 Malarin Ave.
 Santa Clara, CA 95050 USA
 Tel. (408) 529-5755
vnatale@forgottendiseases.org

7. Dr. Natale has explained this study to me. I may contact her if I have any questions.
8. I will be given a signed copy of this consent form, the Study Description, and a copy of the Experimental Subject's Bill of Rights to keep.
9. **PARTICIPATION IN RESEARCH IS VOLUNTARY.** I have the right to decline to participate and to withdraw at any point in this study without jeopardy.

If I want to participate, I should sign this form.

Date	Signature of Study Participant, Parent or Legal Representative
	Name of dependent: _____

Date	Signature of person obtaining consent
	Valerie AI Natale, Ph.D.