Q: What is this study about?

A: The MyTree Study was designed to find out more about why immune disorders, known genetic conditions, abnormal growths including cancers, and blood disorders occur in some people at a very early age. We are also interested in learning more about why these conditions seem to cluster in some families.

Q: What are people in MyTree working towards?

A: We are working towards:

• Creating a network of people including families who would like to learn more about why immune disorders, known genetic conditions, abnormal growths including cancers, and blood disorders occur at an early age or seem to occur more often in their family than others.

• Collecting biological samples to help answer these questions.

• Including unaffected individuals as controls to help answer these questions.

Q: What are participants asked to do?

A: If you participate, we will ask for the following:

Saliva sample. If you are willing, the saliva will be collected using a kit that is sent through the mail.

Short questionnaire. The questions we will ask are about the number of family members, medical history, family health history, and personal habits such as smoking.

Other samples. Some people participating in this study will have had samples collected and stored at a hospital or clinic. If this is the case we will ask for permission to see if there is any leftover sample. We have a form that we would ask you to review and sign that would give us permission to check with the hospital/clinic. We will request only a portion of the leftover sample.

Release medical records. Some people will also be asked to provide permission for us to obtain copies of their medical records from hospital, clinic and laboratory reports relating to diagnosis and treatment of immune disorders, known genetic conditions, cancers, blood disorders, and similar conditions, if applicable.
Q: How much time will it take?

A: The screening will take less than 15 minutes. Completing the questionnaire will take 30 minutes. Sample collection takes about 15 minutes.

Q: Why do you want saliva from me and my family?

A: Saliva contains DNA. To understand if things in the DNA (such as genes) are important in early onset conditions, we need to compare the DNA from people with the condition to people without the condition.

Q: What are you going to do with the cheek cells/DNA?

A: It is known that some environmental factors, such as toxic chemicals, can cause chronic conditions. There are some genetic factors in people which can predispose or make it more likely for themselves or their children to develop chronic conditions. Some conditions are caused by a combination of factors, including the environment and genetics. Some conditions, including many in children, probably result from a change or error during growth of one cell in a person's body and are not caused by other factors, such as the environment or genetics.

We are asking for a small sample of saliva from you and your family members so that we can look at genes that may be important in immune disorders, known genetic conditions, abnormal growths including cancers, and blood disorders.

Q: Can we see the DNA results?

A: There is no clinical or predictive value to this type of analysis. Therefore, the individual results will be kept confidential and will not be made available to parents, physicians, or their insurance companies.

Q: Can I receive the results of the study?

A: Yes, just let us know that you would like a copy of the results. No individual data is studied so only group results will be available.

Q: How do I get started?

A: To see if you may be eligible for the study, you can call us at 1-866-434-9879 (toll free) or 612-625-3910 or you can complete the screener questionnaire found online at http://z.umn.edu/mytreestudy.

Q: Who is the doctor in charge of the study?
A: Logan Spector, PhD phone number 1-866-434-9879