Dear parent/caregiver/legal guardian,

From Leiden University Medical Centre (in the Netherlands) we have started a study into the functioning of children and adults with a change in the FOXP1 gene. This study is a designed in close collaboration with (other) parents of children with FOXP1 syndrome and colleagues all over the world. The aim of this study is to learn more about the independence, development and behavior of children and adults with FOXP1 syndrome.

For this study we would like to ask you to complete an online questionnaire. The questionnaire takes about 3 hours to complete. The data is collected, sent and stored coded (not traceable to your son/daughter) and encrypted (not accessible to others).

To verify the DNA variant that was found in your son/daughter, we would like to ask you to send us the letter from the clinical geneticist, or to give permission to request this letter at the Department of Clinical Genetics where your son/daughter was diagnosed.

Your answers and the answers of other parents will be used for a medical scientific article. When the study is completed, you will receive a copy of this article, along with a short laymen's summary and (where possible) advice for the care and screening of your son/daughter.

If you agree to participate in the study, you can send an e-mail to foxp1@lumc.nl. The researchers will then contact you to provide more detailed information.

Thank you for reading this letter.

Sincerely,

Saskia Koene, clinical geneticist in training
Gijs Santen, clinical geneticist
Leiden University Medical Centre, the Netherlands