

# Leigh Syndrome Global Patient Registry Enrollment Instructions



Before registering, please create your Clinical Research ID (CRID) at [www.thecrid.org](http://www.thecrid.org) (this takes less than 2 minutes). You will enter your CRID in the final question of the registry survey.



Complete the CoRDS activation form: <https://cords.sanfordresearch.org/activation-form>. Under disease name please select “Leigh Syndrome”. Please use a desktop/laptop computer or tablet.



A username will be generated based on your name. You will need to create a password and security question, then click “LOGIN” to access your CoRDS Patient Registry profile.



Complete CoRDS Standard and Leigh syndrome surveys. It is important to enter genetic mutation on QUESTION 4 of Leigh syndrome survey (if known).



Once you have answered all the questions, click SUBMIT.



Update your answers at any time by going to CoRDS: <https://cords.sanfordresearch.org/account/login> and clicking “Update Questionnaire”.