



SJS/TEN Survivor Study: Genetic Risk and Long-Term Outcomes

Location: Vanderbilt University Medical Center

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Stevens-Johnson syndrome and toxic epidermal necrolysis (SJS/TEN) are life threatening but potentially preventable drug-induced diseases with high mortality and understudied long-term morbidity. We are recruiting individuals who have been diagnosed with Stevens-Johnson syndrome/toxic epidermal necrolysis (SJS/TEN) to assemble one of the largest data and DNA biobanks of SJS/TEN internationally. This will be used to identify the nature and risk for long-term complications of SJS/TEN and genetic risk factors associated with drug induced SJS/TEN that will translate into improved pre-prescription preventive strategies and care of SJS/TEN.

If you are interested in being a part of our study, please review the study requirements below and complete our survey. We anticipate a lot of interest so be sure to allow for ample time for our study team to respond.

This study requires

This study requires review of medical records during the time of SJS/TEN diagnosis and treatment. If you participate, you'll be asked to submit your medical records to the study team to be reviewed by a panel of dermatologists. Individuals who continue in the study will be mailed an Oragene kit to their home and asked to provide a one-time oral saliva sample. Participants will complete a series of questionnaires about their physical and mental health since their SJS/TEN diagnosis.

Who can participate?

Adults & Children who have self-identified as having SJS/TEN related to a medication/drug they have taken
Willingness to sign an informed consent document to participate in a research study
Ability to provide medical records or be able to obtain your medical records to the research study personnel. Medical records must be during the time you had SJS/TEN.

Interested in this study? Complete our survey at the link below:

<https://redcap.vanderbilt.edu/surveys/?s=WDKRMTR9J9>

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Institutional Review Board

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