

VTE Family-based Research Study to Identify VTE-susceptibility Genes

Studies of twins and families indicate that venous thromboembolism (VTE) risk (including deep vein thrombosis and pulmonary embolism) is partly inherited. Inherited changes within genes are known to increase the risk for VTE (e.g., Factor V Leiden, Prothrombin G20210A), and much research has been directed at identifying other genes that may increase the risk for VTE (termed "VTE-susceptibility genes"). One way to discover VTE-susceptibility genes is by studying families in which the risk of VTE appears to be very high.

We are pursuing family-based studies of VTE. We are particularly interested in identifying families in which: 1) three or more blood-related family members have had VTE and are alive; 2) at least one brother or sister has had VTE and at least one older brother or sister without VTE is alive; and 3) at least one daughter or son has had VTE and both parents and their children are alive.

We have designed a public web site so that a person with a high VTE-risk family (i.e., a family that meets the above criteria) may visit and complete three web-based questionnaires. This will allow us to construct family trees, and learn more about race, family ancestry and medical history that relates to VTE.

If any of your patients are potentially interested in participating in this important research project, please suggest that they go to VTEfamilysurvey.isl.net and follow the instructions provided. Completion of the questionnaires may take approximately 30-60 minutes. If your patients have questions, they can send an e-mail to vtfamilystudy@mayo.edu and a study coordinator will reply to their questions. If your patients do not have internet access they may still participate in this study by calling this toll-free number, 877-472-4302. They should leave their name, address and phone number, and a paper copy of the questionnaire and consent form will be mailed to the address provided.

If it is felt that the patient's family is likely to provide further valuable information, the patient may be contacted at some future date to provide more information regarding their family and to provide a saliva sample from which their DNA will be extracted for research purposes. At that time they will be given the option to participate or decline further study. This initial study will not ask the patient to identify any family members by name.

We emphasize that visiting this web site and completing the questionnaires is completely voluntary. All provided information will be kept strictly confidential. Any publications that use this information will be of a summary nature only and will not identify any specific individual or family. If, at any future time, the patient should decide not to participate in this study, all of their provided information will be destroyed upon receipt of a written request. All information (including genetic information) discovered from this study will be of a research nature only. Since such information is inappropriate for counseling or decision making, neither the patient nor their family will receive any of the information discovered from this study.