

Invitation: Participation in Platelet Type von Willebrand Disease (PT-VWD) Study

The overall aim of this project is to investigate the occurrence of platelet type von Willebrand Disease (PT-VWD) among patients who, based on clinical and laboratory data, are provisionally diagnosed as type 2B VWD. This study addresses the question of whether PT-VWD is being under- or misdiagnosed in this cohort of patients. The correct discrimination between the two disorders is critical because it directs the treatment decision. The apparent rarity of PT-VWD may be, at least partly, due to the fact that the diagnosis of this condition is missed because of the high degree of similarity with type 2B VWD. Dr. Othman proposes a molecular genetic approach to make a conclusive discrimination.

Under the auspices of the International Society for Thrombosis and Haemostasis (ISTH) and the Scientific and Standardization Committee on von Willebrand Factor, Dr. Maha Othman has established a registry for patients with PT-VWD. She has also secured funding to support the transport of specimens to the laboratory at Queen's University in Kingston, Ontario, Canada and to perform the molecular testing required to discriminate these 2 types of VWD. She will perform the molecular tests and report the results on individual patients back to the laboratory that has provided the patient sample. Further information about this project can be viewed at the PT-VWD website at URL: <http://www.pt-vwd.org/>

Because of the rarity of the condition, identifying and testing patients from as many locations internationally as possible is critical. If your laboratory has identified any patients with either PT-VWD or Type 2B VWD, you are encouraged to contact Dr. Othman to obtain details regarding entering consenting patients and shipping samples.

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NASCOLA member laboratories are being contacted on behalf of EQATH (External Quality Assurance/Assessment in Thrombosis and Hemostasis), a worldwide consortium of organizations involved in assessing and improving the quality of diagnostic laboratory testing for bleeding and prothrombotic disorders. EQATH evolved beginning in 2005 and NASCOLA contributed importantly to its evolution. EQATH is chaired by Dr. John D. Olson, the vice chair is Dr. F. Eric Preston, and the secretary is Dr. William L. Nichols.