

Statement of informed consent for research study and registration of my history of illness as part of the study titled "*Phenotype and genotype correlation in hereditary TTP (Upshaw-Schulman Syndrome)*"

Patient:

Surname: First name:

Date of birth: Gender:

Investigator:

Surname: First name:

- My physician has informed me about the sequence and purpose of the study titled "*Phenotype and genotype correlation in hereditary TTP (Upshaw-Schulman Syndrome)*". I have obtained, read, and understood the patient information provided for the study. Furthermore, any questions I have had relating to participation in this study have been answered to my satisfaction.
- I had sufficient time to arrive at my decision to participate in this study voluntarily.
- I will receive a copy of the patient information and will receive a copy of the signed informed consent statement.
- I have been informed about the scientific investigations regarding genes, proteins, or other factors, which will be conducted as part of the study in question.
- As part of this study, I give my consent that any blood that is taken for the study to be stored for an undetermined period of time, and likely several years, at the study centre (University Hematology Clinic, Inselspital, Bern) and that it may be used for additional scientific investigations. These investigations will serve to better understand congenital ADAMTS13 deficiency / hereditary TTP (Upshaw-Schulman Syndrome) and/or to improve the diagnosis and treatment of future patients who have this or a similar illness.
- As part of this study, I give my consent for (i) personal data, such as name, date of birth, gender, and medical data to be collected in connection with Upshaw-Schulman Syndrome and stored at the study centre (University Hematology Clinic, Inselspital, Bern); (ii) for this information to be sent to the Clinical Trials Unit (CTU), Inselspital Bern University Hospital, CH-3010 Bern, Switzerland for the purpose of data processing; (iii) for my physician, specialists at the Bern study centre, specialists of the CTU Bern responsible for data processing, and persons appointed by the CTU to have access to my stored data; (iv) for this information, except for the name, to be accessed by additional individuals domestically and abroad as part of research into Upshaw-Schulman Syndrome and to develop treatment guidelines; (v) for domestic authorities to be able to access my data.
- I understand and accept that the regulations of other countries governing data protection are not necessarily consistent with those of Switzerland. Confidentiality will be protected.
- In the event of publication (in a professional journal, or on the Upshaw-Schulman website of the University Hematology Clinic, Inselspital, Bern), all data will be rendered anonymous and coded such that my personal identity cannot be discerned.
- Participating in this study will benefit me in that, over time, recommendations based on the evidence will become available regarding my treatment, measures in specific risk situations, or a regular plasma prophylaxis.
- I may withdraw my consent to participate at any time without providing any reason and without there being any negative impact on me or my family members. In the event my participation in the study is terminated, any bloods samples that have been taken from me and are still in storage will be destroyed. The collected data, however, will not be deleted.
- Neither I nor my family members will incur any costs for participating in this study. However, I also have no entitlement to financial compensation.
- My physician will receive the results of the investigations performed and will discuss them with me. He/she will be regularly informed about progress made in the study and about developments in the area of hereditary TTP (Upshaw-Schulman Syndrome).

Location, Date..... Patient Signature.....

Location, Date..... Signature of Investigator.....