

Dear Colleagues,

the end of the year is approaching soon, and we are looking back on a successful year for the Hereditary TTP Registry with some key achievements. In the past year, emphasis was put on data verification and cleaning in preparation of the first publication. In 2019, follow-up data completion and verification will be central to our activities. We are looking forward to embarking on new partnerships and increase recruitment. On behalf of the whole study team in Bern, we would like to say a big thank you for your collaboration and participation.

Best wishes,


Johanna Kremer Hovinga

HIGHLIGHTS OF 2018

RECRUITMENT IN 2018

ORAL PRESENTATION AT THE ASH

COLLABORATION WITH USA STRENGTHENED
TTP REGISTRY DATABASE UPGRADE LAUNCHED

OUTLOOK 2019

FIRST PUBLICATION TO SUBMIT
FOLLOW-UP DATA VERIFICATION

RECRUITMENT IN 2018

In 2018, the Registry was in contact with medical professions, patients and their family members, involving about 50 potential participants from around the globe. From these participants, 8 cTTP patients with 4 family members were enrolled, while seven patients were diagnosed not having cTTP. The other patients are still being screened or are pending to be enrolled.

The biggest challenge for enrolment is the organization of the IRB or ethical approval at the sites, which takes its time and effort. During the last year, the development of an upgraded database has contributed to a slower enrolment too, but we plan to catch up in 2019 when the database will be open for new sites.

HEREDITARY TTP REGISTRY AT THE ASH MEETING

Last December 1-4, the 60th ASH Annual Meeting and Exposition took place in San Diego (CA, USA). The Registry participated with an oral presentation on the data from 123 confirmed cTTP patients. The meeting was a success and created a lot of opportunity to discuss and network. The abstract presented can be accessed via:

<https://ash.confex.com/ash/2018/webprogram/Paper112095.html>



USA-COLLABORATION STRENGTHENED FOR MORE RECRUITMENT

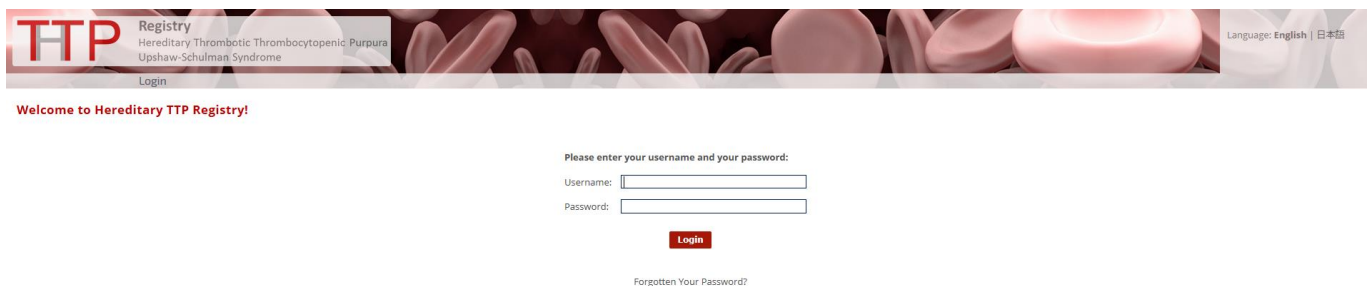
During the ASH 2018, Prof. James George and Dr. Sara Vesely from the University of Oklahoma Health Sciences Center, Oklahoma City, USA, and Dr. Anette van Dorland discussed the situation and potential for recruitment and enrolment of patients from the USA. They efficiently put together an action plan, which will be implemented early 2019.

Together with the newly started collaboration between the Registry and the BloodCenter of Wisconsin, we are looking forward to increasing enrolment of participants from the USA.

Photo (from right to left): Sara Vesely, James George, and Anette van Dorland

TTP REGISTRY DATABASE UPGRADE LAUNCHED

In 2018, we have intensively worked on a database upgrade. The data will be moved into a newer version of the web-based electronic database system, which is more user-friendly and includes an integrated data monitoring system. At the same time, we took the opportunity to optimize the case report forms for easy data entry and high-quality data collection. New sites will be able to enroll patients in the new system from 2019 onwards. Data from existing sites will be migrated in a next step. The database (former and upgraded version) can be accessed via the study's website www.ttpregistry.net, by clicking LOGIN.



FIRST PUBLICATION TO BE SUBMITTED EARLY 2019

A first manuscript is being prepared and will be finalized by the end of the year. We thank our Steering Board member and initiator of the Registry, Bernhard Lämmle, for his help in getting the publication ready for submission early 2019. The manuscript will focus on the enrolment data, highlighting key findings.

**We kindly thank the NFG Foundation
for their donation in 2018**



International TTP Day

Raising funds for Research
Saturday, September 21, 2019
Save the date

FOLLOW-UP DATA VERIFICATION PLANNED FOR 2019

Completion of follow-up data and their verification will be an important activity for 2019. Participating sites may be contacted for data queries and/or clarification. If necessary and desirable by the site, we can pay a visit. In view of the data migration into the upgraded database, a site visit can help to go through this process efficiently too.

www.answeringtpp.org

THANK YOU ON BEHALF OF THE WHOLE STUDY TEAM

The whole study team in Bern would like to say THANK YOU for your continuous support to the TTP Registry. We would especially like to thank the patients and their family members for their participation. Without their participation, we cannot gain insights and further create awareness for the hereditary form of TTP.

Wishing you and your family the very best wishes for the New Year and we are looking forward to another year of partnership.

