**VWF Database**

**VWF Subcommittee**

- Person responsible (Chair / Principal Investigator): Anne Goodeve (UK) / Dan Hampshire (UK)

- **Aim / Mandate of the project:** The ISTH-SSC VWF Online Database aims to provide both research and diagnostic laboratories working on von Willebrand disease (VWD) and von Willebrand factor (VWF) with easy access to the wide range of information available: Searchable lists of mutations and polymorphisms located within and adjacent to VWF; References for published mutation and polymorphism data; ISTH-SSC guidelines on VWF nomenclature; Descriptions of the various VWD types; Annotated reference sequences for VWF; Diagrams of the VWF gene, mRNA and protein; Examples of multimer gels for VWD type 2 defect.

- **Methodology (in very brief, not more than 1 paragraph):** Researchers can submit data to the database via the website. The website is managed by Dan Hampshire (UK) ([www.vwf.group.shef.ac.uk](http://www.vwf.group.shef.ac.uk)). Steering Committee for evaluating the information that is submitted: Anne Goodeve, Reinhard Schneppenheim (Germany), Paula James (Canada), Dan Bellissimo (US), Luciano Baronciani (Italy), Pierre Boisseau (France) and Steve Keeney (UK).

- **Inclusion / recruitment criteria (if applicable):** every researcher can submit his VWF mutation or variation data

- **Year of starting:** 2000

- **Annual report of project:** Dan Hampshire (UK) gave an update on the activities regarding the VWF database. Two major alterations have been made to the online locus-specific database for von Willebrand factor (VWFdb) over the last year: 1) A VWFdb steering committee, consisting of 8 members from 6 different countries, has been established (Dan Hampshire (UK), Anne Goodeve (UK), Reinhard Schneppenheim (DE), Paula James (CA), Dan Bellissimo (US), Luciano Baronciani (IT), Pierre Boisseau (FR) and Steve Keeney (UK)). This committee will oversee classification of VWF variants submitted to VWFdb and will recommend enhancements to VWFdb. 2) A new VWF mutation/polymorphism registry has been created in the Leiden Open Variation Database (LOVD) format following steering committee consultation. The new registry will go live September 2011 and will contain previously unavailable fields for phenotype documentation, along with a “live summary” of sequence variants on the database and will simplify submission of variants to VWFdb. In addition to these two major alterations, several other modifications have been proposed and were discussed. Manuscript Goodeve & Hampshire, Semin Thromb Hemost 2011;37:470-9.

- **Year of completion (expected):** will be ongoing continuously