

## ARTICLE 9 – ACCESS TO EHDN DATA AND BIOMATERIALS

### 9.1. Principles.

- 9.1.1. Ownership of Clinical Data and Biomaterials. Clinical data and biomaterials remain the personal property of the research participant providing them. Such data and biomaterials may only be used by investigators for research upon and subject to the terms of the informed consent of the research participant providing them.
- 9.1.2. Sharing Data and Materials. EHDN is committed to enabling well-powered, informative Studies of Huntington's disease by making data and biomaterials provided by patients and collected through the efforts of contributing sites available to competent scientific investigators who propose ethically sound Studies. In exchange for receiving the data and biomaterials, when ethically feasible EHDN may require researchers to promptly submit Study-level data derived in the course of the project back to EHDN to further annotate the data and biomaterials used.
- 9.1.3. Other Compliance. Members conducting Studies using data or biomaterials obtained from EHDN are also expected to comply with the provisions of this Constitution and to the policies and procedures adopted by EHDN pursuant hereto including the provisions relating to Publication and Authorship and Ethics and Conflict-of Interest.

9.2. Application for Access to EHDN Resources. Any member of EHDN may make application to EHDN for access to EHDN data or biomaterials or both by submitting such information as the Executive Committee may, by policy and procedure, prescribe and by providing such other information as the SBAC or the Executive Committee may request.

9.3. Science: Bioethics Recommendation. The SBAC shall review each application for access to EHDN data or biomaterials and submit a report thereon to the Executive Committee, including such conditions for granting access as the SBAC deems appropriate in the circumstances. In deciding whether to recommend giving access to data or biomaterials or both, the SBAC may consider the aims, objectives, scientific and clinical adequacy of the Study, the availability of the biomaterials sought, the qualifications and capabilities of the investigators, the mechanism for funding, the sponsorship of the proposed study, ethical issues and any other factors it deems appropriate in the circumstances.

- 9.4. Access Criteria. In deciding whether to grant access to data or biomaterials or both, the Executive Committee shall consider the report of the SBAC and may consider any other factors it deems appropriate in the circumstances.
- 9.5. Conduct. All EHDN data and biomaterials shall be used in accordance with this Constitution, the policies and procedures adopted by EHDN pursuant hereto and all applicable laws and regulations.
- 9.6. Policies and Procedures. The Executive Committee may adopt policies and procedures to give effect to these data and biomaterial access principles, including specification of the information to be included in an application for access to EHDN data and biomaterials.