



HUNTINGTON STUDY GROUP ETHICAL AND CONFLICT-OF-INTEREST GUIDELINES

Members of the HSG should maintain the highest personal and professional standards in conducting clinical trials and research. All potential conflicts of interest must be disclosed and inappropriate conflict of interest avoided. The term “conflict of interest” is defined as any financial (i.e., compensation in addition to regular salary support) or other interest that conflicts with the service of the individual because it 1) could significantly impair the individual’s objectivity, or 2) could create an unfair competitive advantage for any person or organization. For purposes of this Article XII, an HSG member is broadly defined to include an investigator, coordinator, data processor, statistician, consultant, or any person involved with and privy to information regarding HSG studies. Additionally, board members, officers of the HSG, and members of the Executive Committee (hereinafter referred to as (“HSG Leadership”) must conform to a higher standard in that they represent the HSG. The HSG Leadership must avoid or manage activities outside of their direct involvement with the HSG that conflict with the mission, goals, interests or reputation of the HSG.

We agree to the following guidelines:

1. HSG members have an obligation to act in the public interest and should be committed to educate the scientific and Huntington disease communities. HSG members agree that such practices are permitted provided there is no disclosure of confidential information or any potential for jeopardizing the successful outcome of any clinical trial in progress.
2. HSG members shall not benefit financially as a result of their participation in and knowledge of HSG studies that are in progress until the earlier of 1) publication of the primary, peer-reviewed research report; 2) such time when the Steering Committee for the study determines that no such publication will occur; or 3) after an interval of one year after the study database is closed. In particular, HSG members who are participating in an HSG study or trial agree not to own (in whole or in part), purchase or trade in the equity of a company or entity whose drugs, biologics, devices, products or intellectual property are being investigated by the HSG (“involved entity”). Any ownership in the equity of an involved entity must be disclosed. “Involved entity” is further defined as an entity that may directly benefit from the performance or outcome of an HSG sponsored study, including without limitation, an entity whose drugs, biologics, devices, or products are being investigated by the HSG in which that member is participating in the study. Further, HSG members or their immediate family members (including spouse and dependent children) shall not in any way or manner benefit financially from the information obtained as a result of their participation or knowledge of HSG studies. HSG members further agree not to inform or influence relatives, friends or others in financial transactions regarding the involved entity. For members of the HSG Leadership, these conflict of interest requirements are applicable to all HSG studies and activities. Steering committees for each study agree to identify involved entities associated with each study and inform participating HSG members. Although steering committees may not be aware of all potential conflicts of interest, HSG members are

expected to exert vigilance regarding conflicts of interest and inform the steering committee on learning that a conflict of interest may or does exist. The steering committee may submit a written recommendation to the Standards Committee if further input is warranted. If there is a concern of conflict of interest of one or more member(s) of the Standards Committee, then the issue may be reviewed by the Executive Committee if further final adjudication is warranted.

3. HSG Leadership and HSG members who are participating in a HSG study sponsored by an involved entity agree not to earn or receive personal compensation from the involved entity in relation to the intervention under investigation from the date that an agreement between the sponsor and HSG is executed until 1) publication of the primary, peer-reviewed research report, 2) such time when the Steering Committee for the study determines that no such publication will occur, or 3) after an interval of one year after the study database is closed. For HSG members, if such financial relationships already exist prior to study involvement, they must be disclosed, reviewed, and approved by the study's Steering Committee prior to participation in the HSG study. For HSG Leadership, these financial relationships must be disclosed according to Section 7 below. These relationships may need to be suspended or terminated. HSG members may serve on steering committees or safety monitoring committees and receive compensation for such services for clinical studies sponsored by involved entities provided that compensation and duties are stipulated in a written agreement and disclosed in an annual conflict of interest declaration.
4. HSG Leadership and HSG members who are participating in a HSG study sponsored by an involved entity may participate in other research activities funded by an involved entity provided that 1) the activity is not related to drugs or products for the same indication which is under investigation by the HSG; and 2) that compensation and duties are stipulated in a written agreement and are commensurate with the research activities that are being conducted, disclosed in an annual conflict of interest declaration, and in turn reviewed and approved by the appropriate steering committee and reviewed, approved and managed by the Standards or Audit Committee, as appropriate.
5. HSG members who are not participating in an HSG Study sponsored by an involved entity may participate in selected activities such as lectures, educational programs, consulting with that involved entity provided that any compensation received for the selected activities is commensurate with the activities.
6. If members of the HSG Leadership consult with involved entities and potentially involved entities on behalf of the HSG, to the extent allowed by existing confidentiality agreements, must disclose to the Audit Committee the purpose of these meetings, the amount and destination of fees paid, and outcome of the meetings. Any compensation received for the consulting must be commensurate with such activities.
7. There are two types of disclosure forms: 1) study-specific disclosures and 2) disclosures required of members of the HSG Leadership (as defined above). Disclosure forms must be completed on an annual basis or whenever there is a change in the status of the HSG member regarding potential conflict of interest. Failure to fully disclose conflict or perceived conflict of interest constitutes an ethical violation, and may lead to dismissal from the HSG. HSG Leadership disclosures will be reviewed by the Audit Committee of the HSG.
8. Members of the HSG should insist on full and meaningful disclosure of financial support for educational events to which they are invited to participate.

9. Members of the HSG should fully disclose their research support and any significant financial interest with manufacturer(s) of commercial products related to the topic of their presentation for education events in which they participate.

Name (print)

Signature

Date