

Referral to Coordinating Center

Institutions may choose to become junior collaborators who refer patients for enrollment at the coordinating center at the NYU School of Medicine. Patients would be enrolled through NYU School of Medicine, but Collaborative Champions would be asked to assist with completing or arranging the blood draw. Your institution may allow this without IRB approval at your institution, with limitations (per OHRP guidance <http://www.hhs.gov/ohrp/policy/engage08.html>, Section III, B, 1).

- Briefly discuss the study with eligible patients and give the family a study flyer (provided by the HDRC coordinating center)
- Interested patients will directly contact the study coordinator at NYU School of Medicine. The study coordinator will provide further information through email and/or phone conversations and obtain informed consent.
- Consented participants will receive a study kit in the mail that includes study consent forms, medical and family history questionnaire, medical records release form, and blood collection tubes with packaging.
- Participants will complete study materials at home and contact the referring physician to arrange blood draws.
- Blood samples can be returned to participants, and all study materials will be packaged in provided materials and shipped to the coordinating center at NYU School of Medicine via FedEx at the coordinating center's expense.