Active Enrollment

Collaborative Champions directly enrolling patients at their institution into the HDRC study will need to work with the coordinating center at NYU School of Medicine to obtain IRB approval at their institution. The NYU School of Medicine study coordinator will be available to provide documents and assistance as needed for IRB approval at other institutions. Once IRB approval is secured, Collaborative Champions would be asked to:

- Identify eligible patients at their institution and discuss the study with them in detail
- Obtain informed consent for those who wish to participate and collect signed consent forms
- Collect operative and pathological reports from diagnosis and surgical management of Hirschsprung disease along with needed signatures for medical records release
- Complete study questionnaire with assistance of participating families
- Obtain blood samples for affected individuals, and parents if available – 3-5 mL of whole blood is requested for infants under 1 year of age, 5-6 mL of whole blood is requested for children 1-11 years old, and 17 mL of whole blood are requested for children 12 years and over and from parents (detailed instructions are provided for registered Collaborative Champions)
- Ship all study documents and sample to the coordinating center in provided packaging via FedEx, at the coordinating center's expense.