What is the purpose of the study?
The purpose of this study is to evaluate and collect data on infants born with Heterotaxy syndrome. Investigators will study outcomes in infants that have not undergone a Ladd procedure for development of intestinal problems. In addition, researchers will assess risks of Ladd procedures.

Who is eligible to participate in the study?
Infants born with Heterotaxy and have not had a Ladd procedure may be eligible to participate.

What does the study involve?
Participant’s health records such as intestinal symptoms, data about intestine or heart surgeries if they are necessary, any complications from surgery, past health information, and test results will be collected by physician and/or nurses. Other physicians involved in the subject’s care may be contacted to gather information as well. Subject health information will be collected until 5 years old. Any information gathered about the subject will not have identifying information; only birthday and hospital number will be collected. Only the team taking care of the subject will know his or her name.

What are the benefits?
There will be no benefits to individual subjects from this retrospective review. Information learned from this study may help us better understand those factors that influence outcomes in this population and to develop and refine best treatment practices. The information gained from this study will assist researchers, physicians and other clinicians who care for children with Heterotaxy Syndrome to better understand the outcomes associated with the condition and to improve future care and treatments.

What are the risks?
The only risk of this study is the potential loss of confidentiality. Care will be taken to avoid this risk.

Is there any compensation for participating?
There is no compensation for participation in this study.

How will I get more information about the study?
Interested parents will discuss the study with a member of the research team and will be given a parent permission/consent form that further explains all of the details of the study. Study procedures will not be started until the parent(s) fully understands what is involved in the study and has signed a parent permission/consent form.

Status: Recruiting
Site(s): Advocate Children’s Hospital-Oak Lawn

Who should I contact for more information?
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