What is the purpose of the study?
The purpose of this research is to study motor development and the use of the General Movements Assessment and the Infant Motor Profile in infants with complex congenital heart disease.

Who is eligible to participate in the study?
Infants with complex congenital heart disease may be eligible to participate.

What does the study involve?
Subjects will be video-recorded in the first three months for 3-5 minutes long during an appointment with the pediatric cardiologist. In addition, subjects will have video-taped standard of care developmental assessments at 6, 12, and 18 months of age. These assessments involve testing the patient’s gross motor, fine motor, speech and language, cognitive, and adaptive skills using toys to prompt the subject to play as recommended by the American Heart Association and American Academy of Pediatrics as standard of care evaluations.

What are the benefits?
No direct benefits can be guaranteed by participation in this research study. However, researchers may learn more about motor development of children with congenital heart diseases that require surgery in the first month of life. Researchers may also learn if the quality of general movements in early infancy helps to tell us about child development at 18 months. This information may be useful to identify children who would benefit from therapy intervention at an early age.

What are the risks?
Participation in this study will not put subjects at any greater risk of adverse events than other children with congenital heart disease. The developmental assessments will be done in the same way as during routine care, the only part of this study that is research is the use of video recording.

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 Campus, Advocate Children’s Heart Institute

Who should I contact for more information?
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