

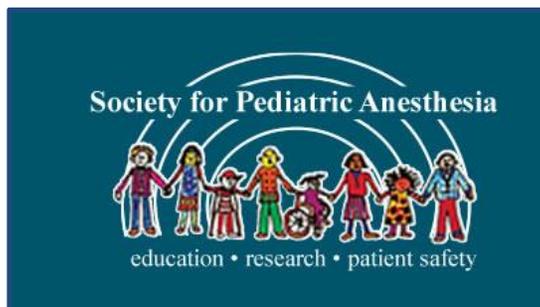
Thank you for your interest in our research! Inside you will find the answers to many frequently asked questions about the study.



BOSTON CHILDREN'S HOSPITAL

For more information please call Dr. Joseph Cravero at 617-355-7737 or e-mail joseph.cravero@childrens.harvard.edu.

A Quality Improvement Initiative from the Society for Pediatric Anesthesia Improvement Network (SPAIN)



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BOSTON CHILDREN'S HOSPITAL
HARVARD MEDICAL SCHOOL
DEPARTMENT OF ANESTHESIA

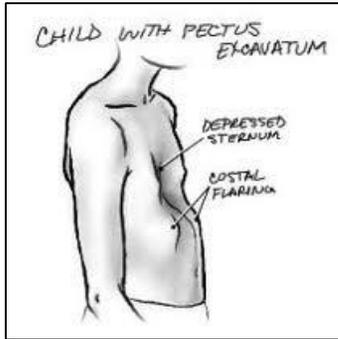
Development of a Chest Wall Deformity (*Pectus Excavatum*) Operative Outcomes Registry



Seeking youth (ages 8-30) with chest deformity

Q. What is Pectus Excavatum?

A. *Pectus Excavatum* is the most common chest wall deformity (~1 in 400-1000 births).



Q. What is an outcomes registry?

A. Doctors make patient registries to understand the techniques they use better and to see how well and safely patients respond to them. A registry may be a collection of medical information combining records from lots of patients to study a specific disease or condition. Here, we are combining electronic operating room records, anesthesia records and operative notes, progress notes, and behavioral questionnaires collected from youth having surgery to correct *Pectus Excavatum* in a single **Operative Outcomes Registry**.

Q. What does the study involve?

A. After surgery, we will review your electronic medical records to learn more about your surgery, your anesthesia, and your recovery afterwards. At two weeks and three months later, you will be asked to complete a behavioral stress questionnaire and to rate your pain, list any pain medications, and assess your daily functioning.



Pectus Excavatum Anesthesia Management



Corrective Surgical Care

Q. Are there any risks associated with being in the study?

A. There are no medical or surgical risks because we are not making any changes to your routine care at Boston Children's Hospital. The only possible risk is to your privacy. When we analyze your information, we will not be able to tell it has come from you or your family. All data will be kept on secure computer networks at Boston Children's Hospital and the Dartmouth Bioinformatics Group at Dartmouth College.

Q. Will my care be different?

A. We will not make any changes to your surgical care. Additionally you will receive exactly the same anesthesia management and medical care after surgery as if you were not in the study.

Q. Why is the study important?

A. This study takes place at Boston Children's Hospital and up to 20 other hospitals, each confidentially sharing information in a new registry for managing youth with *Pectus Excavatum* having corrective surgery. We do not know which surgery procedures and pain control methods before and afterwards are best. By combining information, we hope to gather enough data to understand better how youth can have good outcomes after surgery and getting anesthesia (e.g., less pain; a faster recovery; a smoother return to school or work).



Q. Who will see the study information I give and my results?

A. Doctors at the hospital where you have your surgery will replace your name with a code so that only they will know which data is yours. Once your name has been removed, the results you contribute will be combined with information from other youth having surgery in the **Pectus Excavatum Operative Outcomes Registry** (maintained at Dartmouth College).

Q. How do I sign up? **A.** Call or e-mail Dr. Joseph Cravero at 617/355-7737 or joseph.cravero@childrens.harvard.edu.