

## Surgery/Invasive Procedures for Infants with Trisomy 13 or 18

The risks and benefits of anesthesia and surgery/procedure need to be carefully explained to the family in close collaboration with the surgery, procedure and/or anesthesia teams. An infant's candidacy (or not) for any particular procedure or intervention should be carefully discussed and justified so that the multi-disciplinary team is clear about the clinical judgments made.

### Issues and questions to address:

- What are the goals of procedure or surgery?
  - To facilitate discharge? Full repair? Palliate (i.e. not complete repair but improvement in function or ease of care)? If palliative, what is the plan if there is long-term survival?
  - To learn more about a diagnosis? If so, how does what will be learned help the family reach their goals? Are the risks worth the knowledge learned?
- Are there medical options for treatment that should be considered as an alternative to surgery or the procedure considered?
- What are the risks? What other anomalies or diagnoses are present that may complicate the surgery/procedure? For example, infants with Trisomy 13 or 18 may not extubate as quickly as infants without that underlying medical diagnosis, requiring longer hospitalization. Pain control may be more difficult as the overlap between adequate pain control and respiratory depression may be greater in this group of patients. Do these considerations affect the parents' view of risk and benefit?

### Procedures for patients at UNC Hospitals with Trisomy 13/18:

Note: Every infant's combination of diagnoses is unique so early consultation with the appropriate surgical team is crucial if interventions are to be discussed and considered. All procedures below would be considered in the context of other diagnoses on a case-by-case basis.

#### PEDIATRIC SURGERY

- In absence of more complex cardiac disease or other substantive comorbidity that would alter surgical risk, the surgery team would intervene for esophageal atresia/TEF, imperforate anus, or any similar congenital obstruction or anomaly if it would improve quality of life. Gastrostomy tube placement may be offered to facilitate care at home.
- ECMO, dialysis catheter.

#### CARDIAC CATHERIZATION and SURGERY

- Decisions regarding the appropriate catheter-based or surgical interventions would be made on a case-by-case basis. Patients may be referred to another center with more experience.

#### ENT

- In absence of more complex cardiac disease or other substantive comorbidity that would alter surgical risk, the surgery team would consider performing a tracheostomy and other ENT procedures.