

## Guiding Principles for Care of Patients with Trisomy 13/18

### **1. Communicate diagnoses and prognoses with accuracy and sensitivity.**

How diagnoses, prognoses, and care choices are imparted to families is important in supporting their informed choices as well as overall welfare. Terms used to describe Trisomy 13 or 18 should be both accurate and selected with sensitivity to these issues.

### **2. Select interventions based on the child's medical condition, best interests and parent's preferences.**

Intervention choices for infants and children with Trisomy 13 or 18 should be made based on the child's medical condition, best interests, and parental or guardian goals and preferences. Intellectual disability alone is not an appropriate factor in limiting care options offered to families.

### **3. Offer a range of appropriate medical options with an understanding that individual family decisions may vary widely.**

Family decision-making may vary widely based on individual factors, including values, past experiences, and family circumstances. Reasonable medical options should be offered equally for medically similar situations. Options offered initially may also need to be reassessed as circumstances and prognoses evolve.

### **4. Consider decision-making an evolving process.**

Care preferences may change over time, as families gain experience, knowledge, and build relationships. It is therefore important to consider decision-making as an ongoing process.

### **5. Provide continuity of care with clear communication among providers.**

Continuity of care, and coordination of communication demonstrate respect for patients and families and decrease the risk that important information will be lost for any party.