there are limits to what clinicians and hospitals are obligated to provide, and they should follow established processes as described elsewhere.[13]

Recognition of a wider potential range of outcomes, often with the use of some degree of technological support, for infants with T13/T18 has led to a shift toward shared decision making for these infants and children. There is now a more explicit recognition of the plurality of values, spiritual beliefs, and moral norms around care of infants with medical complexity, developmental disability, and shortened lifespan. This has led to considerable attention to T13/T18 in the medical and ethical literature and imparts a need for guidance for pediatric clinicians to offer family-centered and appropriately individualized care to these children. The principle of justice requires consistency in offering or denying specific medical interventions for all children, including those with T13/T18, within and between institutions and geographic areas. Furthermore, there needs to be recognition that implicit bias and structural inequities have the potential to introduce and perpetuate disparities, such as when those families with greater resources are able to travel to a "trisomy-friendly" hospital to access LSIs for their child that would otherwise not be available to them. The well-documented influence of implicit biases around gender, race, ethnicity, socioeconomic status, etc, should not play a role in what is or is not offered to families, and thus, should be assessed prior to meeting with expectant parents.

BRIEF CLINICAL BACKGROUND

Table 1 provides a basic overview of trisomy 13 and trisomy 18. Prior to the availability of fetal ultrasonography and prenatal genetic screening and testing, these syndromes were diagnosed at birth on the basis of hallmark constellations of congenital anomalies and recognized pathognomonic phenotypes among infants with full T13/T18. In resource-abundant health care settings, many of these infants are now identified before birth with noninvasive prenatal screening (NIPS), although the diagnostic certainty for this test may be lower than some parents realize, without subsequent amniocentesis and correlation with specific physical findings.[14]

Trisomy 18 was first described in 1960 and is the second most common chromosomal trisomy syndrome after trisomy 21 among live-born children. It occurs in 3/10 000 live births and occurs 2 to 3 times more often in female than in male live births.[15] Many congenital anomalies are associated with T18, most commonly uteroplacental anomalies; prematurity; neurologic disabilities ranging from general abnormalities of tone and neurodevelopment to persistent, severe issues including seizures; and possible endocrine or hormonal abnormalities; characteristic facies; hand anomalies; and congenital heart disease. T18 has historically been associated with high mortality in the immediate neonatal period and the subsequent year after birth. Approximately 95% of live-born infants with T18 present with full trisomy (with increased risk as maternal age increases), although cases of mosaic and partial T18 have been well described and have more variable clinical presentations.[16,17]

Trisomy 13 was first described in 1957 and occurs in 1.35 in 10 000 live births.[15] Many infants with T13 have major structural central nervous malformations, and all will have significant lifelong neurocognitive problems. Broadly, T13 is characterized by multiple midline anomalies including cleft lip and/or palate, congenital heart disease, scalp defects, and abdominal and pelvic abnormalities. Like T18, T13 is most often associated with a full duplication of the chromosome and increased risk with advanced maternal age, and the mosaic and partial forms have milder presentations.[17]

PRENATAL DIAGNOSIS, CARE COORDINATION, AND DECISION MAKING

There is a robust body of literature exploring the scientific and ethical complexities of prenatal screening and testing, which includes multiple options for all expectant parents

TABLE 1. Important Differences in Epidemiology and Outcomes for T13/18[15,49,62,63]

	Trisomy 18 (Edwards Syndrome)	Trisomy 13 (Patau Syndrome)
Incidence (Note: very high rates of pregnancy terminations in all studies)	3.02 per 10 000 live births (US) 2.6 (International) 4.8 (Europe)	1.35 per 10 000 live births (US) 1.15 (International) 1.9 (Europe)
Liveborn rate	13.5% (US)	18.9% (US)
Survival beyond first week for liveborn infants	52.5%	43.1%
Survival beyond first year for liveborn infants	10–25%[a]	10–25%[a]
Survival beyond 5 y for liveborn infants	12.3%	9.7%
CHD	80–90%	57–80%
Severe CHD	20%	17%

[a] Variable by study/interventions provided.